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ABSTRACT

This collection of readings is intended to help parents of children with disabilities join together or with professionals to advocate for inclusive recreational programs for their children. The following 15 readings are included: "To Play or Not To Play? A History of Recreation in America" (Carla E. S. Tabourne et al.); "Why Is Inclusive Recreation Important?" (Stuart J. Schleien et al.); "Why Is a Family Focus Imperative to Inclusive Recreation?" (Jennifer Mactavish); "Working Together for Programs of Quality" (Leonard Weiss et al.); "Focusing on Families as the Point of Service" (Jennifer Mactavish and Linda A. Heyne); "Getting Action by Taking Action: Parent Advocacy" (Maurice K. Fahnestock and Jonathan A. Balk); "Building Relationships and Friendships through Recreation" (Linda A. Heyne); "Paving the Road to Inclusion with Cooperation" (John E. Rynders); "Emphasizing Abilities across the Lifespan--Why Bother?" (Carla E. S. Tabourne and John E. Rynders); "Family Focus Groups in the Dowling School Friendship Program" (Linda A. Heyne); "Customer Service Builds Better Programs: Bloomington Parks & Recreation" (Maurice K. Fahnestock and Crystie Dufon); "After School...What Do You Do? Minneapolis Y-MAP" (Jonathan A. Balk et al.); "Family-Centered Recreation Programs: The Pallina Club & Family Rec Connections" (Kathy Strom); "Mixing Kids & Seniors at the JCC Intergenerational Program" (Linda A. Heyne et al.); and "Inclusion in Community Leisure Services" (Stuart J. Schleien). (Each paper contains references.) (DB)

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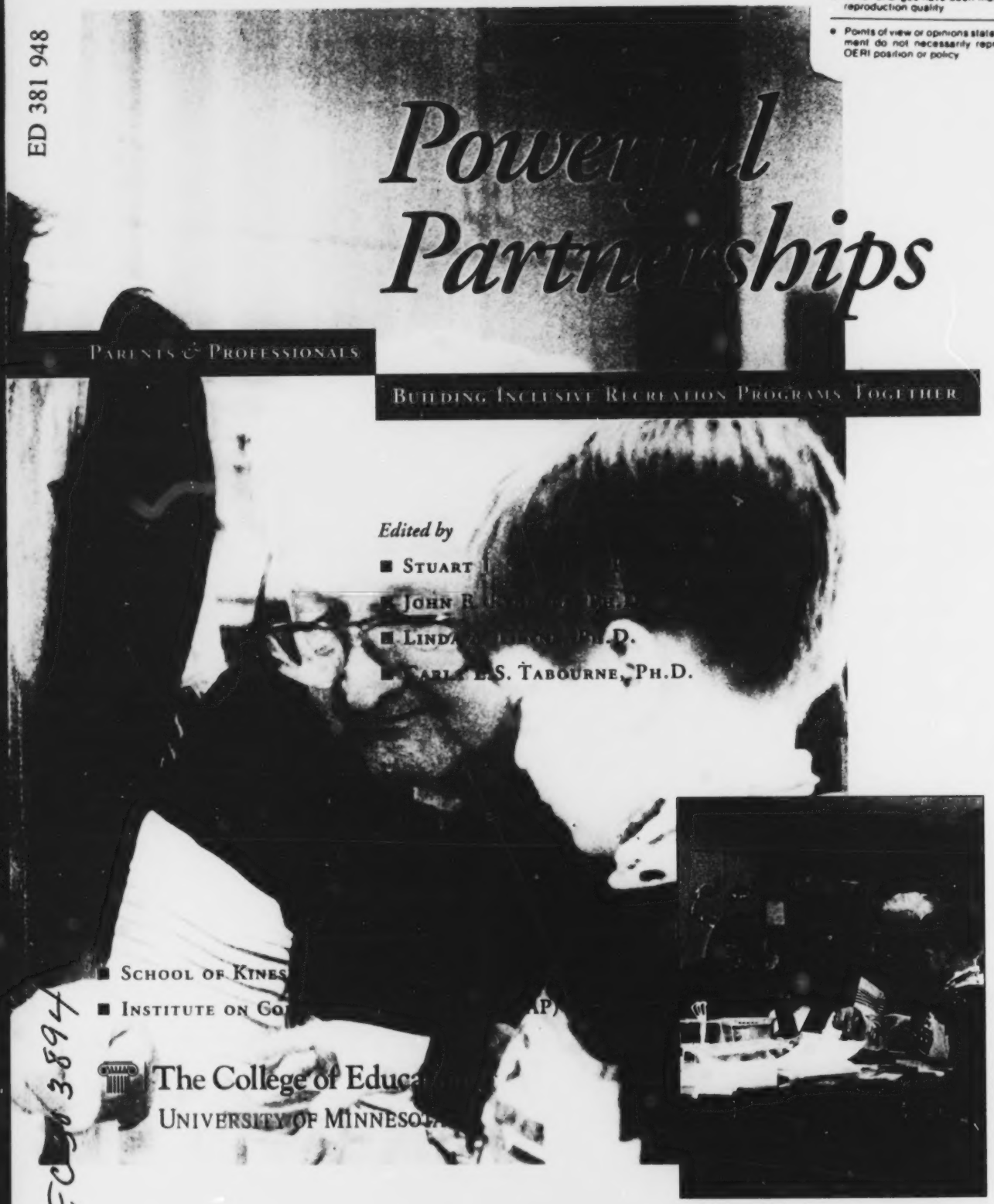
Powerful Partnerships

Parents & Professionals

Building Inclusive Recreation Programs Together



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Powerful Partnerships

Parents & Professionals Building Inclusive Recreation Programs Together

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Foreword: Parents as Advocates

Susan Hamre-Nietupski
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It has been almost fifteen years since the passage of federal and state laws providing the right to education in the least restrictive environment for all children with disabilities. Yet, parents still frequently find that they must "fight the system" to secure an inclusive education, especially for children with disabilities. When parents persist in asking for inclusive services, they often are forced to choose between a segregated school or recreation program with all its services and an existing integrated program in which such services may not be available and/or the curriculum is inappropriate. When this occurs, parents are placed in the difficult position of choosing between what they are told is a quality, though segregated, program and an integrated program of lower quality.

Rather than forcing parents to make these choices, communities should strive to provide quality services in inclusive settings. Unfortunately, as many parents know, such a view is not shared in all communities. It may be necessary, then, for parents to join together as advocates, or enlist the support of other advocates, to secure the option of a quality inclusive recreation program in a regular public school or community recreation agency. As Des Jardins, an authority on parent advocacy, has said so well, "Parents not only make effective advocates, they have the potential to become the best advocates – because they have the sense of urgency needed to motivate them to do what is necessary to move bureaucracies, and they can identify with other parents because they have been there."

In this publication, methods that have been used to secure quality inclusive recreation services are discussed. These methods are based on our experiences as parents and advocates who have been working together for over four years toward inclusion. We recommend that these methods be used in combination and over an extended period of time, in whatever order is best for a particular situation. A summary of these methods follows.

- **Form a Group:** An important step in advocating for change is forming a group of individuals with similar concerns. Group size is not as important as is the commitment of willing members, since advocacy for change can be time-consuming and frustrating. Plan to meet on a regular basis with a specific agenda. And, agree on an amount of time to spend on agenda items so each meeting "stays on track." Initially, the group should decide on a small number of common goals to complete within a specified time period. Periodically, review progress made toward meeting these goals. When initial goals are met, new ones need to be set in order to maintain momentum. At this point, the group should continue meeting, but possibly less frequently. Look for other advocates/interested persons to meet with the group. For example, if the group is comprised of mostly parents,

consider asking others such as university faculty, teachers, therapeutic recreation specialists, and interested relatives and citizens to join. Such persons offer new perspectives and can serve as resources.

- **Be Informed:** Obtain accurate information on the legal rights of individuals with disabilities and their parents; this is available from advocacy organizations such as the Association for Retarded Citizens-United States (Arc-US), The Association for Persons with Severe Handicaps (TASH), the National Therapeutic Recreation Society (NTRS), or from a legal advisor with expertise in the area of disability rights. Also, obtain accurate information about successful methods of including children with disabilities through current books and journals.
- **Keep Others Informed:** Provide readable, accurate information to other persons needing to make informed decisions. This would include other parents, regular and special education school principals and staff, therapeutic recreation specialists and community recreation personnel, local district and regional education administrators, board of education members, and influential persons in the media. Consider writing a brief, easy-to-read position paper on why inclusive options should be provided in your community, including examples of how inclusive options can work successfully. Consider presentations to meetings of other related groups such as local/state chapters of the Arc, TASH, NTRS, or your local PTA. Plan to present to local civic groups such as Kiwanis/Lions/Rotary clubs and to religious organizations. Presentations should focus on what inclusion is and is not, its methods, present and future goals, and on answering questions. Visual aids such as slides showing children with disabilities who already are integrated interacting with peers without disabilities can be very effective.
- **Influence Policies on Inclusion:** Key change agents, such as recreation administrators, often have little information on the inclusion possibilities for children with disabilities. Increase their awareness by contacting them personally, providing verbal as well as written information. Some agency administrators have only recently begun to draft inclusion policies. Know when park and recreation boards meet and what agenda items are scheduled for a particular meeting. Be prepared to present your position relating to the inclusion issue. Often it is possible to influence a boards' early drafts of written policies by vocalizing your position during hearings/meetings. Be aware that it may be necessary to sign up in advance to speak at meetings, especially at the state level. When boards are writing/rewriting policies, they frequently set up committees to write the policies and report back to the board; volunteer to serve on such committees to be sure your position is considered.
- **Work with the Media:** The media often present traditional "status quo" information about persons with disabilities and the inclusion issue. Persons representing the media need to be made aware of new information about recreational alternatives. Influence media presentations on an ongoing basis, visiting influential persons such as TV/radio station managers and newspaper executive editors to share information about the inclusion issue. Provide media representatives with a list of resource persons whom you know are both knowledgeable and supportive of inclusive recreation services. Since others, such as park and recreation board members, usually have an easier route to media contact, it is crucial that the media also listen to your position.
- **Meet Frequently with Influential School and Community Recreation Administrators:** Initiate meetings with influential administrators from the municipal park and recreation board, preferably those who make policy and programming decisions involving children

and youth with disabilities. Constructively, but firmly, present your group's goals for inclusive options, then cooperatively discuss effective ways to meet those goals. Continue to initiate contacts in order to have discussions in the future.

- **Influence Others in the Community Recreation System:** Many recreation departments have consumer advocacy boards composed of a variety of "consumers," including parents and other advocates. One or more group members should volunteer to serve on such a board to provide positive input on inclusion. Work to inform and influence other persons who actually report to influential administrators, for example, the therapeutic recreation specialist.
- **Work with Other Advocacy Associations:** Group members may already be involved in organizations such as the Arc, TASH, NTRS, or other specific disability support groups that also are advocating for rights for persons with disabilities. Members of your group might serve on committees of other advocacy groups. It is common, for example, for a local/regional Arc chapter to have a recreation committee; membership on such committees could influence policy positions and actions on inclusion issues.

As in most advocacy efforts, the task of securing quality inclusive options for children and youth with disabilities is a lengthy process and can be discouraging at times. It is therefore essential to use methods such as those suggested here continuously, over time. The future results will prove well worth the effort – seeing people with disabilities living, working, and spending their leisure time integrated into communities with peers without disabilities.

PART ONE

Inclusive Recreation— Past & Present

To Play or Not to Play? A History of Recreation in America

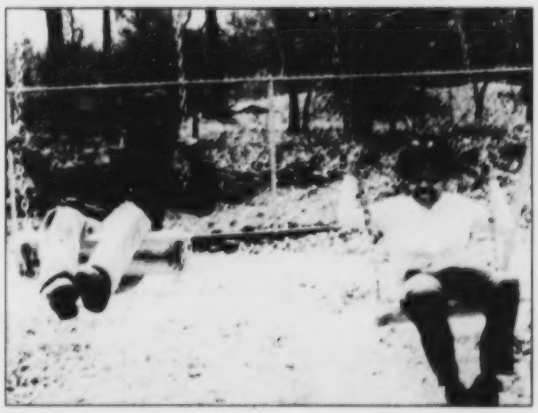
Carla E.S. Tabourne
Stuart J. Schleien
P. Craig Dart

The simple answer to the important question *Why recreate?* is *to enhance the texture of our lives.* Why be concerned with such an intangible issue? Because in the fabric we call *America,* the threads of basic survival – spirituality, culture, humanness, work, and recreation – are not as finely woven as in other cultures. Rather, these fibers are spun piecemeal as the economy dictates. The result is unsettling, stressful, and forever in need of patching. Laws are passed and then amended to help us interpret the Constitution and the Bill of Rights. A quick review of American history will illuminate this premise particularly as it relates to recreation and persons with disabilities.

■ The Seventeenth, Eighteenth, & Nineteenth Centuries

Prior to the Industrial Revolution and urbanization of the 1800s, most families' income was based upon agriculture. Survival depended on work and even children were required to contribute to the economic support of the family. Nonproductive time was viewed as detrimental: play was limited and even considered sinful. Anyone who could not work hard, produce something, or contribute to the family was not valued. People with disabilities who had no opportunities to make such contributions were, therefore, not valued. People with disabilities were usually segregated, out of sight, living in institutions or hidden in homes. If they worked in the society they were denigrated and exploited through discriminatory practices.[1]

The Civil War, which left behind a large number of men with disabilities, helped change this perception. They were war heroes and, because they could not be hidden, public awareness about people with disabilities grew. By the end of the 1800s people with disabilities who lived in institutions began to be treated more humanely. Professional organizations that served people with disabilities were established. These organizations sought to provide better teaching strategies and educational preparation for professionals working with people with disabilities.



■ The Early Twentieth Century

With industrialization and the mechanization of farms, many people moved to the cities to work. Work hours changed, which led to an abundance of free time. For many, the changes in work schedules and the new urban

environment meant changes in lifestyles. Many people misused this free time and the availability of commercial leisure services by frequenting bars, houses of prostitution, and other activities viewed as socially and spiritually destructive. Sports and leisure activities began to be seen as desirable alternatives to these socially unacceptable behaviors. Organized religious groups revisited the ancient Greek view of sports and leisure as a means of achieving the "sound mind in the sound body." However, few facilities existed for organized recreation. For example, public playgrounds were very uncommon at this time, existing only in large cities like Boston and New York. In 1906 the Playground Association of America was organized and many cities followed the example of larger cities and instituted public playgrounds. The first sand lots and playgrounds were constructed particularly for immigrant children and people who lived in tenement housing. They were built as safe havens from crime and other dangers of city life and to provide opportunities to socialize with other children.[2] This *playground movement* spread across the country and continued until World War I.

With the advent of World War I, many men and women began to work in factories or joined the armed forces. The goal of community-based organizations was to build a national community. Community recreation centers were used to build federalism and to teach skills to the work force. School houses, settlement houses, community centers, and other community-based establishments worked to build a homogeneous, loyal, patriotic society and to acculturate immigrants; the U.S. was a melting pot and differences were not accepted or valued. The community-based organizations took responsibility to help solve another concern: what to do with military personnel.

When servicemen frequented local communities, drinking, prostitution, and venereal disease became common problems. Community organizations responded to these problems by providing recreation activities for soldiers. Additionally, recovering soldiers experienced recreation in hospitals and, upon discharge, they carried their new interests home. Increased survival rates of injured soldiers, due to such new medical advances as sterile surgery, meant that large numbers of men with disabilities were reintroduced into communities. Hospital recreation programs for soldiers were being shared with other medical facilities. Due to overcrowded facilities in the early 1900s, many patients were placed in tents on hospital grounds. These patients showed incredible recovery and "tent treatment" was born.

As programs were developed for adults injured in the war or in factories, they were also being developed for children with disabilities. Additionally, many after-school programs for children with disabilities were initiated during this period, and assessments were made to determine how much money would be allocated for each individual's disability.[3]

The prosperity of the 1920s came to an end with the Depression and, once again, many people were left with a large amount of free time. Believing this excess free time would be squandered, programs such as the Civilian Conservation Corps, which built numerous recreational facilities funded by the federal government, were created. These programs greatly enriched public recreation in the United States. The economic instability of this period also promoted the Social Security Act of 1935. This act provided federal grants for maternal aid, child health and welfare, and services for children with disabilities. During this time, public concern about the welfare and care of people with disabilities grew considerably, although problems continued to be experienced when people with disabilities attempted to coexist with the nondisabled public. Children with disabilities were typically placed in institutions immediately after birth. Some institutions offered recreation activities for their residents, but these activities rarely involved anyone other than staff members and other residents.

With the advent of World War II, America was again drawn into a war economy. Great numbers of Americans were wounded, and subsequently treated and rehabilitated in hospitals that served people with newly acquired disabilities. The Veteran's Administration and

the Red Cross provided recreation activities for wounded soldiers as a form of therapy. Diversionary activities provided valuable rest and renewal for hospitalized soldiers. Wheelchair sports, such as wheelchair basketball, were offered. Responding to the veterans' interest to continue to participate in wheelchair sports after discharge, the National Wheelchair Basketball Association was established in 1949 and, later, the National Wheelchair Athletic Association was founded. The Veteran's Administration and Red Cross played critical roles in the development and use of recreation as a form of therapy, thus further developing the field of therapeutic recreation.

In the community, programs for people with disabilities became more prevalent. Children's summer camps had existed since the 1860s, but camps for children with developmental disabilities were not established until the 1940s. As children and adults were observed participating in activities in ways that surpassed the expectations of the public, a new question emerged: *How can persons with disabilities be helped to lead productive lives?* Assessments were made not only to determine how much federal assistance persons with disabilities should receive, but also to determine possible strategies for rehabilitation.[3]

■ Post World War II to the Present

The end of World War II presented cities with a new phenomenon. Military men, returning home from the war, typically took advantage of government financial packages for mortgages and special housing, and they and their families often left the large cities to find quieter lives in the suburbs. At home, many inventions like the lawn mower, washing machines, and frozen foods made daily chores less time-consuming. As a result of the increased income and discretionary time, and the recent relaxation of the war-time military machine, leisure opportunities for the middle class became an important aspect of life. Consequently, family units became the focus of recreational activities.

Between 1947 and 1963, involvement in varied forms of recreation ballooned. Visits to national forests increased by 474 percent, to national parks 302 percent, and overseas travel increased by 440 percent.[4] Suburban areas and small towns across the nation legislated to develop park and recreation facilities and programs to meet their growing recreational needs.

While life in the suburbs was improving, inner cities began to decline. As the more affluent middle class moved to new suburban communities, the neighborhoods they left behind were re-populated by economically disadvantaged people, usually minorities and immigrants. This middle class exodus left a lower tax base which resulted in less support for urban park and recreation facilities and programs. Overcrowding, a condition of poverty, led to a general lack of open space. Some of the urban riots that occurred during the 1960s were expressions of frustration with conditions, including the denial of minority access to adequate recreation opportunities during the hot summer months. The riots themselves have been described as a deviant form of play, discharging tension that had built up for years, and the result of boredom and frustration.[5] Where there were ample opportunities for recreation and sports, positive outcomes occurred. In time, minority athletes who had great skills were accepted into major league teams in baseball, football, and basketball. Access to recreation opportunities led to increasing numbers of minority athletes becoming active in college athletics, then moving into professional sports as athletes and later as coaches.

During the Civil Rights movement and into the 1970s, the nation's youth began to question established values and institutions. The young people rejected and attacked the artificial constraints, rigid curricula, and lack of self-governance that ruled their lives. In response, many institutions relaxed their social restrictions to recognize the rights of minorities, women, homosexuals, and people with disabilities. By the mid-seventies, a research report

showed that only one of five persons surveyed found work a greater source of satisfaction than leisure.[5] The 1970s were a period of "consciousness raising" and emphasis was put on the "human potential." Abraham Maslow's doctrine of self-actualization became very popular and many Americans sought to explore their own identities more fully. When work did not allow for self-actualization or opportunities for rewarding self-expression, leisure became an acceptable venue. Recreation was considered an excellent vehicle to become connected with oneself and, as a result, work became more of a source of funding for recreational endeavors.[6] The many radical social changes that took place during this era had a substantial impact on recreation. The humanistic thinking of the time promoted play for all within a noncompetitive, open-to-all framework.

The consciousness-raising and individualism of the 1970s ran rampant and led to the identification of young people in the 1980s as the "Me" generation. Attaining quick personal and financial success became the singular focus and motivation for decisions regarding career choice, marriage, and parenthood. This younger – often more highly educated – work force influenced the work environment for everyone. During the 1980s, the average American worked longer hours due to factors including an apparent resurgence of a work ethic or to intensified competition as some positions were eliminated by improved technologies and the emergence of new occupations. Moreover, people exacted more demands on the job for opportunities to grow and expand personally and professionally. For many, work was no longer just the "job" as it may have been in the 1970s: it was now a career that included some of the previous decade's self-fulfillment demands. The demand for recreational opportunities also continued to increase in the 1980s; however, recreational activities became more structured and planned in order to compensate for decreased leisure time and a growing concern for physical fitness.[7] While more affluent people were spending more money on leisure pursuits, private contributions to non-profit agencies and government spending for public agencies providing recreation decreased. Beginning in the late 1970s and early 1980s, recreation became big business – an economic commodity to be purchased like other goods. As a result of decreased funding for recreation and rising costs, people of lower economic means were finding it increasingly more difficult to gain access to leisure opportunities. This decline in affordable recreation and leisure opportunities for people with average or lower-than-average incomes continued into the first years of the 1990s. How the current changes in the House and Senate affect allocation of funding for public services remains to be seen. Specifically, the changes in philosophy will translate into allocation of funds for public recreation depending on whether recreation is seen as a possible solution to current problems in society.

Why is Inclusive Recreation Important?

Stuart J. Schleien
Carla F. S. Tabourne
P. Craig Dart

During the 1970s, many advances in civil and human rights for people with disabilities were made, resulting in a decrease in institutional placements and a movement toward the provision of expanded, quality community services. One impetus for change was the public exposure of and outcry against harsh treatment of residents in many state hospitals throughout the country. For example, the neglect and cruelty uncovered at the Willowbrook State Hospital in Staten Island, New York, caused law professor Drew Days to write:

> *We realized also that as citizens these people have legal rights. They have the right to be removed from the community only when absolutely necessary and only after certain procedures have been followed. Anyone deprived of liberty and confined to an institution should be entitled to decent living conditions and proper treatment and care. These are legal rights. These are civil rights as fundamental as the rights to vote, speak, or worship freely...*[1]

In the two decades between 1967 and 1987, the daily population of persons with mental retardation living in state institutions in the United States dropped more than fifty percent from 194,650 to 94,696. As a consequence, children with disabilities who may previously have been placed in institutions are now staying home with their families. Children who do not remain with their biological families are placed, whenever possible, in foster homes or with adoptive families rather than in state-operated institutions, intermediate care facilities for persons with mental retardation (ICF/MRs), nursing homes, or group homes. Family members are taking on more responsibilities in caring for children who have disabilities and, along with service providers, lawyers, legislators, and academics, have been strong advocates for changes in the delivery of services by schools, vocational centers, residential providers, and various community programs.

Their advocacy efforts have resulted in and been supported by key legislation affirming the rights of individuals with disabilities. In 1973, for example, the Civil Rights Act for the Handicapped made it illegal for any agency or organization to receive federal funds if they discriminated against a person solely on the basis of his or her disability. In 1975, a pivotal year for inclusion, the Education for All Handicapped Children Act (PL 94-142) was passed. This law provided free, appropriate public education in the least restrictive environment for

all children with disabilities, ages five to twenty-one. Recreation was included in this law as a related service. An amendment in 1986 provided educational services for children with disabilities at an even earlier age (birth to age five).

The Shift to Community Recreation

Continuing into the present, further barriers to participation in society by people with disabilities have been made illegal. Though these battles have mostly centered around education and work opportunities, access to recreation was also included. Recreation participation for young people with disabilities in community centers was not common until recently. Generally, children and youth with disabilities only participated in recreation activities organized and provided by their parents. If these children and their family members approached community centers to seek recreational activities, they often found that staff could not meet their needs or include them in programs. Children and youth with disabilities were often denied community services or were referred to special programs that served people with disabilities only.[2] Municipal and commercial recreation service providers frequently offered (and still offer) one or more of the following reasons for excluding people with disabilities from their programs: A) staff were not trained to serve people with disabilities; B) it was too costly to hire special staff for so few participants without the skills to participate in existing programs; C) their constituents would resist participating with people with disabilities and would go elsewhere (serving people with disabilities was the job of special organizations dedicated to the purpose of providing segregated recreation); D) liability insurance would be prohibitive; E) retrofitting their facilities for just a few people was not in their budgets nor was it cost efficient; and F) they had received few if any requests for services from people with disabilities.

In 1990, the Americans with Disabilities Act was enacted to eliminate discrimination against individuals with disabilities in the areas of employment, transportation, public accommodations, public services, and telecommunications. Of great importance to providers of leisure services, Section 302 of the act prohibits denying full and equal access of any public facilities or services to an individual on the basis of disability. The mandate defines separate, albeit equal, programs and services as discriminatory.

Although recent laws have provided the impetus for agencies to accommodate individuals of varying abilities both architecturally and programmatically, these agencies have often only removed architectural barriers. Many administrators initially find inconvenient or inaccessible facilities to be the major stumbling block to inclusion. To overcome physical obstacles, many community recreation agencies are currently assessing and adapting their *physical* environments, especially because guidelines on physical barrier-free evaluation and design are readily available. However, physical accessibility and physical proximity between people with and without disabilities do not, in and of themselves, ensure positive results. In fact, current research suggests that without *programmatic* access, participants without disabilities continue to view their peers with disabilities and inclusion efforts negatively. As of now, community efforts and strategies to make programs accessible remain few. Recreation service providers must include people with disabilities in socially and physically barrier-free – that is, *totally* barrier-free, zero-exclusion environments where no one is rejected.[3]

Approaches to Social Inclusion

For the most part, two approaches to social inclusion are in practice today whereby people with disabilities can become active recreation participants. The selection of these approaches depends upon individual needs and program availability, and should not be dictated by the

preferences of service providers or the service delivery system itself.

The "inclusion of generic programs" approach can be defined as helping an individual with a disability to select an existing age-suitable community recreation program designed originally for participants without disabilities. The support person works in cooperation with a program leader to identify and eliminate the differences between program skill requirements and the individual's capabilities. People with disabilities participate in activities alongside a natural proportion of peers without disabilities. Participation in existing age-appropriate recreation services has the potential to help people with disabilities to acquire skills required for contemporary, appropriate, high-interest activities in the community. A significant advantage offered by this approach is the potential to develop social relationships between participants with and without disabilities. Generic programs serve the majority community culture unlike segregated programs that often exist in relative isolation, outside the usual community network.[3]

A second approach is referred to as "reverse mainstreaming." In this approach, segregated programs exclusively for people with disabilities are modified to attract peers without disabilities. This approach is currently practiced by Special Olympics International through their Unified Sports Program. Unified Sports combines, on the same team, approximately equal numbers of athletes with and without disabilities, of similar age and ability. Unified Sports leagues have been developed throughout the country in basketball, bowling, soccer, softball, and volleyball. The success of reverse mainstreaming often depends on restructuring a program to make it highly attractive to all participants. Once the participants without disabilities are "in the door," participating alongside their peers with disabilities, social interactions and friendships can be facilitated. For participants with disabilities, interactions and exposure in familiar surroundings and among friends with disabilities remain manageable.[3]

■ Conclusion

It has now become clear why inclusive recreation services have become such an essential ingredient in the quality of life of children and youth with disabilities and their family members. Some of the more compelling reasons why it is now crucial to help make community recreation agencies more welcoming and supportive of all people, with and without disabilities, include: A) greater understanding and acceptance of individuals with varying backgrounds and ability levels; B) personal growth and increased social sensitivity, including improved compassion, kindness, and respect for others; C) positive impact on the social development of all individuals; D) broadened social networks and friendships; E) increased opportunities to acquire and perform lifelong recreation skills; and F) legislation that mandates accommodations.

With powerful laws behind them, children and youth with disabilities and their family advocates are now in an excellent position to change the way that recreation providers offer services in the community. In the future, inclusive recreation services are expected to become the typical medium enabling individuals with disabilities to access their communities and peers. In this manner, everyone who desires access to these valuable and necessary components of a real quality of life will be granted these opportunities. It is this change in service delivery that will result in healthier and happier lifestyles.

Why is a Family Focus Imperative to Inclusive Recreation?

JENNIFER MACTAVISH

As the two preceding articles have illustrated, the field of recreation has undergone many changes since the early days of this century. Among the most significant of these changes is the recognition that recreation plays an important part in the lives of all people, regardless of whether a person has a disability or not. Consequently, we have gone from a time of exclusion and separation to a time when individuals with and without disabilities have greater opportunities to participate together in recreation.

Despite these changes and increases in the number of inclusive programs, recreation participation by people with disabilities continues to be fairly low. Some researchers in therapeutic recreation have come to believe that limited participation, particularly among children with disabilities, is a result of the way in which services and programs are provided. Currently, most recreation service professionals focus solely on the child with a disability and the child's needs upon his or her enrollment in a program. While this approach is important for those who attend programs, it does little to encourage the involvement of non-participants. To reach other children and to improve programs overall, a different strategy is required – one that acknowledges the importance of families in the recreation experiences of children with disabilities.

After many years of study, specialists in therapeutic recreation are beginning to recognize that getting and keeping children with disabilities involved in community recreation is largely dependent on family support.[1] One way of gaining such support is to provide programs that reflect the recreation interests and needs of families. Put another way, understanding families and their recreation is the key to building bridges between the family recreation experiences of children with disabilities and their individual activities in the community. ***Family recreation,*** which is also referred to as ***shared recreation,*** means any activities that two or more members of the same household enjoy participating in together. Participation in these activities can occur anywhere and can take the form of spontaneous play activities and/or more formally organized programs.

To illustrate how crucial this link is, the following sections address current knowledge about the importance of family recreation and its potential to influence the participation of children with disabilities in individual recreation.

■ The Importance of Family Recreation for the Entire Family

Based on numerous studies of families that do not include children with disabilities, we know that family recreation is a valued and important highlight in many families' lives. According to these families, simply spending time together engaged in enjoyable activities helps to strengthen relationships and generally makes for healthier and happier families.

Although it seems logical that the same claims could be made about the importance of recreation in families that include children with disabilities, so far only one study has looked at this issue.[2] In this work, parents from sixty-five families shared their views on family recreation and its impact on their lives and the lives of their children with and without disabilities. From these parents' perspectives, taking part in activities as a family was thought to be very important. They expressed this outlook in many ways, but most commonly noted that shared recreation was a way of "re-establishing a sense of what is important in life." As one parent reported:

> *Life as a family can be stressful... with kids going out to school, both parents working, trying to make ends meet... You get the picture – things can seem like drudgery after a while. So for both of us sharing fun activities with the kids and one another is probably the most important thing we can do as a family to balance things out.*
>
> *So much of life is about getting along – surviving from one check to the next. To me, family recreation is about remembering what's important in life. It's about the best way I know of honoring one another as people and as members of your family.*[2]

Adding to this view, some parents talked about shared recreation as an "integrated experience" that was valuable and important for immediate and extended family members:

> *Everybody in our family lives within five or so miles of here... so almost everything we do includes one or more of them. Andrea does everything we do and I think it's been really positive – she gets to be around people, kids, and adults that aren't handicapped... probably more important though is they get to be around someone who is.*
>
> *When Nicholas was first born my parents and sisters and stuff were pretty freaked out... but going to the cabin, Sunday dinners, and just hanging out together has really helped them get a better outlook on children – I guess you could say "people" in general – with disabilities.*
>
> *I always laugh when they talk about "adaptive rec" and the like, being sort of a new idea or at least something that you people* [recreation service providers] *are into these days... we've been adapting and integrating within our own family for years now...*[2]

Building on comments about the importance of family recreation, parents also spoke at great length about the benefits of taking part in activities as a family. Most of the time these conversations centered on how shared recreation "made families closer," "gave them something fun to do," and "improved quality and satisfaction with family life." Three different parents expanded on the meaning behind each of these family outcomes:

> *Making and keeping love and compassion between all of us is a priority in this family. The time we spend together, the activities we do... even if it's just a walk in the park... help us do that. It just helps us bond as a family.*
>
> *Family recreation gives everyone a chance to do something extra – something fun. It's a time to let go of case notes, assessments, advocacy... it's a time to be a family.*

Mainly family recreation helps make us be more satisfied with our family life in general. I guess you could say that it makes the quality of all of our lives better.[2]

While the importance of family recreation in families that include children with disabilities has not received much attention, what *is* known suggests that recreation in these families is as important as it is in families that do not include children with disabilities. That is to say that parents of children with disabilities also view shared recreation as a valuable way of spending quality time together, strengthening relationships, and bettering their overall quality of family life.

■ Importance of Family Recreation for Children with Disabilities

While family recreation offers important and positive outcomes for the whole family, it is said to be especially important for children. After all, it is within the family that most children are first exposed to recreation and begin to learn the skills (social, physical, and recreation) that encourage long-term interests in recreation participation. Based on information provided by parents involved in the study noted above, we know that family recreation holds similar benefits for children with disabilities. What differed, however, was the intense emphasis placed on how these experiences contributed to helping children connect with other family members, develop skills, and set foundations for the future.

I give my child my undivided attention when we do activities together – where else is he going to get that? Also, I do things with him in the hope that they'll carry over to other things he does later on in life.

I try to help our daughter, when we're playing, on the skills she needs so that she might do better later on. The other thing, though, is she's never going to get the kind of connection with other people that she gets with our family. That might be the most important benefit of all – belonging.

Our son is behind in most skills, so one of the benefits to doing things as a family is he gets a chance to work on these things in a fun way and have unconditional acceptance and support along the way. I'm not sure there are many other situations in his life where that is possible... but maybe if he learns how to do some of these things now – at home – he'll have a better chance of making friends to do things on his own with.[2]

The words of these parents express their strong beliefs in the importance of family recreation and the hope that skills learned through family recreation will be useful later on – perhaps in individual activities in the community.

During more in-depth discussions, it became clear that the importance of family recreation shifted as children grew older and as a disability was present or absent. Parents of children with and without a disability under age ten generally viewed activities with the family as extremely important. By the time children without disabilities had reached age twelve or so, individual options became somewhat more important than family recreation. Meanwhile, participating in family activities continued to be the most important recreation outlet for children with disabilities. When parents explained their views on this, their agreement was unanimous. As one parent noted:

Let's face it... as much as they say things are changing and as much as I hope they are, family recreation is really the only option for our two with disabilities. Well, at least the

option that we can really be sure about. As for the other ones – it's just natural at their age to want to do their own thing. Recreation-wise it's just so much easier for them... they can go off to the park or some kind of program and we don't have to worry all the time about them being okay.[2]

In short, parents attributed the ongoing importance of family recreation to a lack of individual recreation options, as well as concerns that those options that were available would not provide positive experiences for their children. These views were not necessarily based on negative past experiences, but were picked up in discussions with other families and, more often, from impressions left by recreation service providers themselves.

■ Parents' Views on Community Recreation Service Systems

In talking about the things that made it difficult for families to take part in recreation together, parents almost invariably expressed concern about the messages – the information – they received from recreation service agencies. Most of the time these conversations revolved around frustrations about marketing and promotional materials that did not provide enough information, or the kind of information needed to decide whether existing programs were appropriate and of interest. Parents often tied this frustration to their difficulties in finding individual recreation programs for their children, but also related them to identifying activity options for their families. In explaining their frustrations, two parents captured those of many others:

I eliminate a lot of things because of the messages I pick up from the information recreation places give. If they told me about stuff like – is the place accessible, do they have the equipment we need to take part, do they have co-ed bathrooms, a place to change diapers, who to call if I have questions... then I'd have something to go on. There just has to be a better way of communicating with people – welcoming and encouraging tax-paying potential customers. Why do I always have to do all the calling and digging?

I'm always looking through the information that comes from parks, the Y – we have a family membership at the Y. They all seem to have that generic statement, something about no one being excluded... yet I never find anything in it that makes me feel like they really want me to call or to come. So even though we belong – we pay our dues – it's just not all that inviting... so we don't go and do as much as we would like as a family and we sure don't send our son off to do things on his own.[2]

Concerns with the quality of information about recreation services highlights two important points. First, service providers have the potential to positively and/or negatively influence family recreation and the participation of children with disabilities in individual activities in the community. Second, parents not only provide children with their first exposure to recreation, but they serve as "gatekeepers" to their activities outside the family.

■ Summary of the Importance of a Family-Focus in Inclusive Recreation

Like other families, those that include children with disabilities view family recreation as a valuable and important part of life. Recreation strengthens family relationships and provides children, particularly those with disabilities, chances to learn lifelong recreation skills in supportive environments. Moreover, because of experiences in family recreation, parents are quite knowledgeable about what it takes to successfully include their children with disabili-

ties in recreation. This knowledge, combined with their perceptions about the lack of quality in community programs, has made parents cautious gatekeepers when it comes to activities outside the family – especially for their children. To change this situation, strong bridges need to be built between families and providers of recreation services. This can be done by making certain that families and their recreation interests and needs receive uppermost attention, which, in turn, will put recreation professionals in a better position to communicate and demonstrate an interest and willingness to work with families; to support and promote family recreation by providing programs that expand on what is already taking place at home and/or help families recognize the importance of their recreation as a family unit; to understand and develop individual recreation programs for children with disabilities that build on family recreation experiences; and to help parents help their children with disabilities balance participation in family recreation with involvement in individual activities with their peers in the community.

PART TWO

Enhancing Family & Community Development

Working Together for Programs of Quality

Leonard Weiss
John E. Rynders
Stuart J. Schleien

Our experience indicates that the need for recreation, enrichment, community skill development, and socialization will be felt acutely by most families in which a child with a disability resides. Unfortunately, accessing programs with these qualities may seem to be a mystery to them. Some families may not know how to find, much less approach, recreation professionals for assistance. Moreover, they may feel that adaptive services will require large fees or elaborate arrangements. And, they may even feel awkward about asking for services they feel might be seen as unusual.

It is important for families to realize that not only is there a strong movement afoot to integrate recreation programs and facilities for persons with and without disabilities, but also that this movement is spurred by laws to assure this effect. Laws such as the Rehabilitative Amendments of 1992, Individuals with Disabilities Act (IDEA) of 1990, and the recent Americans with Disabilities Act (ADA) are aimed at including people with disabilities into recreation programs exemplifying a least restrictive environment and typical participation.[1]

Why is it then that recreation professionals, armed with both the mandate of law and the badge of their own conviction to provide recreation for all citizens, sometimes appear to back away from inclusionary methods and opportunities? Despite the mandate, training, facility modification, and positive intent, studies have shown that state of the art practices, recognized as effective by professionals, are not always implemented.[2] This is troubling considering that the results of several studies of integration show that cooperative efforts involving parents, professionals, and othe. constituents in program planning, implementation, and evaluation support efforts to conduct inclusionary programming. Hence, guardians, friends, advocates, and parents of children and youth with disabilities not only have the support of law in expecting that the children be included into recreation programs, but their direct involvement at many levels can serve as an essential catalyst.[3]

The most helpful piece of information for supporters of persons with disabilities – from advocates to parents – is that it is their right to receive community recreation services in the least restrictive environment possible. Thus the expectation that recreation professionals should be partners with parents in accomplishing inclusive services is both powerful and correct. Benefits of the synergy that consumers and service providers can generate together is mirrored in the interactions of partici-

pants in the inclusion process itself. Evidence shows that as participants with and without disabilities become acquainted in an inclusive recreation program, the experience elicits many positive responses from participants without disabilities. In developing a greater sense of equity, nondisabled individuals often become active advocates for their peers with disabilities and help identify solutions to inclusion obstacles.[4]

The action which parents take to collaborate with professionals – "greasing the wheel" to bring about inclusionary services – is not only supported by the mandate of law, but is a powerful advocacy effort, bringing together parent-professional commitment, energy, and expertise. Through the power of love and caring, programmatic success is created through the partnership which benefits both individuals with and without disabilities.

■ Ascertaining the Quality of Inclusive Programming

When examining programs to determine the degree of quality and commitment to inclusion, at least three ways of making inquiries will prove helpful to parents. First, they should determine how committed the program administration is to inclusion and what integration processes are being addressed by them. Second, parents can tour the facility and discuss, with both administrators and practitioners, the techniques and methods that are being used to support inclusion. Third, inquiries can be combined with observations of the program activities themselves to see if the program addresses individual needs.

Within each of these categories there are a number of specific indicators of quality that have evolved over time and are based on a variety of sources and practices. These indicators bear out an agency's commitment to providing inclusive services. Questions about the presence or absence of these indicators will lead to an awareness of whether the fundamentals for inclusive programming are in place. Both parents and professionals may ask the following questions of each other with the intention of creating excellence in inclusive recreation programing for all children:

Quality Indicator 1: ***Administrative Policy and Practice***

- Is an inclusionary philosophy reflected in the mission statement and agency profile in the community via brochures, public relations pieces, marketing efforts, etc.?
- Are published policies and procedures in compliance with current laws pertaining to serving persons with disabilities in settings that are as inclusive as possible?
- Is documentation of inclusive services available? Is it clear, policy-compliant, appropriately confidential, and up-to-date?
- Are budget commitments sufficient to support substantial inclusionary efforts?
- Are the opinions of parents, advocacy groups, consumer review boards, decision makers, and other integration-oriented persons solicited by the agency?
- Are staff hired with a background reflecting education and experience in inclusion?
- Are staff given supervision, opportunities for continuing education, and feedback regarding inclusive techniques and practices as part of regular evaluation and support efforts?

Quality Indicator 2: ***Logistical and Environmental Considerations***

- Does programming take place with peers who have a wide variety of abilities, including peers who do not have a disability, with as much community orientation as possible?
- Do modifications for physical accessibility allow for flexibility, with any necessary adaptations for individuals with hearing, vision, and other impairments?

- Are inclusionary costs reasonable and sponsorships available?
- Does scheduling reveal times and places which promote accessibility for persons with disabilities, including access to public transportation?
- Are participants enrolled in programs that are chronologically age-appropriate, reflecting participation in the type of activities typical of the referent age group without disabilities?
- Are avenues provided to keep key players in continued communication with each other?

Quality Indicator 3: *Techniques and Methods*

- Do inclusive program offerings reflect effective inclusive strategies and techniques such as partial participation, companionship training, task adaptation, cooperative learning, teaching of new social and recreation skills with appropriate behavioral techniques (e.g. task analysis, prompting, sequencing, correction, reinforcement, shaping, and fading)?
- Are there ongoing modifications of activities and materials, and appropriate reductions in adaptive devices and techniques?
- Does assessment of skill, experience, and preferences of participants with disabilities occur as part of the program plan and accommodation assessment?
- Is there an ongoing evaluation of the program for assessing environmental and task quality as well as individual leisure needs and preferences, skills, and enjoyment?
- Are there staff who are well trained in how to conduct the program and who are given adequate preparation, administrative support, and sufficient staff assistance?
- Is there a welcoming orientation for participants and families as they are introduced to inclusive programs and adaptive strategies, and an invitation to participate in activity evaluation, assessment, and participation in the activity itself?

Quality Indicator 4: *Individualized Programming*

- Are the activities based on the needs and preferences of participants?
- Are adaptations geared to the individual, as typical and standardized as possible, designed to increase independence within the activity, oriented toward enhancing mastery of recreation and social skills, and planned to fade out when possible?
- Do activities develop skills, leisure knowledge, attitudes, and resource awareness that are transferable to community opportunities, settings, and time constraints of the individual?
- Are allowances made for personal challenge and dignity of risk?
- Do activities afford a spectrum of recreation choice, ranging from spectator participation to interactive types of activities?

These "indicators of quality," framed as questions, can be asked not only by parents but by recreation professionals as well, in examining and planning programs aimed at inclusion on a prospective as well as introspective basis. This focus points to the partnership power of collaborative program efforts, empowering all parties to benefit from the success of seeking mutually beneficial goals in creating effective inclusionary programming.

Finally, parents should not be shy about getting involved, realizing that the pressure generated by informed positions as parents or advocates not only gives the system a "push" in an essential way, but supports officials of the system in fulfilling their mission as service providers to the entire community.

Focusing on Families as the Point of Service

Jennifer Mactavish
Linda A. Heyne

Families can have an enormous influence over the play and social relationships their children build through recreational activities. Likewise, community recreation programming can play a key role, not only in supporting individual family members with disabilities in recreation settings, but in offering and supporting all-family recreation experiences. Because of the powerful influences parents and recreation service providers have on children's play and socialization, clear partnerships need to be established between recreation service providers and parents or other family members.

This article describes the key roles parents can play in influencing their children's recreation experiences and relationships, discusses how family recreation can enhance families and communities, and provides guiding principles to promote inclusion, family recreation, and collaboration between families and recreation service providers.

■ Family Influences in Supporting Children's Recreation

Parents and families affect their children's recreational values and behaviors in many direct and indirect ways.[1] For example, parents may offer their children recreation-related advice or endorse particular social and recreational values. Parents also serve as role models for their children through their own participation (or lack of it) in recreational activities and social relationships. Parents can model actual skills that are necessary to participate in recreational activities; they can also model relational behaviors such as how to communicate effectively, resolve differences, show care for others, and extend oneself. Furthermore, parents indicate the relative importance of such activities through how much time, effort, and enthusiasm they devote to friends and recreation.

For families that include children with disabilities, parents are often the key players in locating community recreational opportunities for their children in their neighborhoods. Many recreation professionals have acknowledged that parents often shoulder the primary responsibility for providing recreation activities for their children.[2] A common image projected in these studies is one of parents who must "knock on doors" to persuade community recreation agencies to serve their children with disabilities. When parents lack faith that their children's needs will be met at a community recre-

ation agency, they often resort to nurturing informal connections in their neighborhood or focusing only on meeting the child's leisure needs at home.

With the relatively recent movement toward inclusive recreation services and the advent of the Americans with Disabilities Act, however, recreation providers have begun to reach out to parents in a collaborative effort to provide services to children with disabilities. Parents – as the people who know their children best – have begun to be involved in the process of inclusion by providing assessment information related to children's needs, abilities, recreation preferences, wishes, and goals. Parents also provide important input regarding how the child's recreation participation fits within the family dynamics, values, goals, and schedules. Additionally, parents are involved in providing professionals with valuable feedback during their children's participation in programs and/or upon completion of the programs. This feedback is typically accomplished through informal communications throughout a child's participation in a program and through surveys or satisfaction questionnaires upon completion of the program.[3] Through these efforts collaboration and communication between families and professionals have begun to be strengthened.

■ Family-Centered Recreation

At one time or another, most families that include children with disabilities have had some contact or experience with providers of community recreation services. These organizations and service providers can influence families and their recreation in many positive (or negative) ways. One of the most obvious ways that service providers can have a positive influence on all family recreation is by offering more family-centered program opportunities. Recreation programming for families can support and promote what families are already doing by focusing on activities that take into account family members' interests and needs, as well as accommodating wide ranges in ages and abilities so the whole family can participate together. Family-centered activities can also provide opportunities for interacting with other families and introduce simple low-cost activities that families can try at home.

In addition to increasing the number of family-centered programs, service providers need to ensure that existing programs are open and willing to welcome all potential participants. In a study of family perspectives on family recreation, parents of children with disabilities often noted that service providers seemed preoccupied with making sure that programs "appeared to be open to everyone"[4] at the expense of neglecting other important issues such as accessibility, staff training, offering adequate supports, or offering programs that were family-focused. Families have stated that these issues would need to be addressed before they would feel comfortable involving their families and children with disabilities in community recreation settings. As a step toward changing this situation, families expected recreation service providers to take the lead by communicating and/or demonstrating that they were prepared to accommodate and welcome all potential participants and that services were, or could be, made available to help make sure that participation took place and was positive (e.g., certified therapeutic recreation specialists were there to help if needed). Additionally, families proposed that an agency contact person be available to address families' questions, concerns, and complaints.

Beyond becoming more responsive to the needs of families who express interest in programs, the quality of information about recreation services and the way services are marketed must also be addressed. When promotional materials and marketing approaches do not provide parents with the information they need to make informed decisions about the appropriateness of programs and services, families – especially those with children who have disabilities – are led to believe that they are not welcome. In other words, when information and

marketing are poor or ineffective, these families often limit or eliminate possible shared recreation options or individualized community-based activities for their children with disabilities. Compounding the possible negative affects of this view is the perception that community recreation programs do not always offer supportive, safe, and positive recreation experiences for children with disabilities.

■ Family-Centered Principles to Promote Inclusion and Family Recreation

The potentially negative influences that can result from a lack of collaboration between parents and professionals point to three important principles that are designed to enhance family recreation and the individual activities of children with disabilities:

- Promoting community recreation participation by families and children with disabilities requires effective marketing of available program options and communicating the potential benefits of these activities to families and their individual members. For example, "selling" programs to families could address such issues as why a program or service is effective; why families should use certain facilities, services, or programs; and what other families have to say about the programs or services that are being offered.
- Actively involving children with disabilities in community recreation requires a shift from simply focusing on the child and the challenges that make his or her participation in programs difficult (e.g., physical or cognitive skill deficits) to the things that make participation difficult and/or impossible in the first place. That is, parents are "gatekeepers" to their children's activities in the community and, as such, family needs, interests, and concerns must be addressed if participation is to be enhanced.
- Keeping families and children with disabilities in community recreation settings requires evidence of program quality, progress, and positive outcomes. In other words, service providers need to ask (and listen to) parents' views on questions concerning whether service providers are delivering what they promised; whether families and/or individuals are getting the kinds of benefits they expected – and if not, why?; and whether families are happy with the quality of the programs and their experiences?

When put into practice, these principles acknowledge the important roles that parents and families play in promoting inclusion and family recreation, as well as strengthen collaboration between families and recreation professionals to provide the most responsive services possible for families and for family members who have disabilities.

Getting Action by Taking Action: Parent Advocacy

MAURICE K. FAHNESTOCK
JONATHAN A. BALK

Capitalizing on the Civil Rights movement for disadvantaged people, the advocacy of visionary parents has succeeded in improving the lives of their children with disabilities, creating their own "civil rights" movement. However, to achieve these significant improvements, parents have often had to use confrontational approaches, including lawsuits, to bring about change. Unfortunately, while sometimes necessary, an adversarial approach sets up an antagonistic relationship between parents and professionals. To produce a positive collaborative relationship, parents and professionals must begin to look together at organizations in their entirety, utilizing a whole systems approach containing four steps:

1 Identify what has gone wrong or is not being done – that is, *why* the advocacy is needed. This provides the rationale, justification, and opportunity for change.
2 Identify what part of the organization is responsible: go directly to the individual *who* has the power to make the change.
3 Call for changes grounded in direction, action, and results – *what* needs to be done.
4 Make a clear request, be assertive, and extend a collaborative offer to build relationships with the professionals in the agency – show *how* to communicate and sustain ongoing positive dialogue for satisfactory results.

This collaborative systems change model[1] seeks to build trust, communication, and supportive relationships between all parties involved in the inclusion process. Although the use of confrontation may be an appropriate final strategy in situations where severe resistance to positive change exists, a thoughtful and systematic advocacy strategy that uses clear requests and educational and collaborative methods is our highly recommended first step.

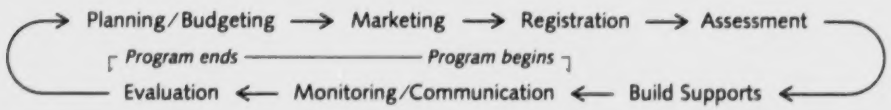
■ Delivery of Inclusive Recreation Programs: *A Model Identifying Why Advocacy May be Needed*

Figure 1 on the next page represents our view of a seven-phase cyclical process for the delivery of inclusive recreational programs.

As the figure shows, inclusive programming begins with annual *planning and budgeting*, followed by *marketing* the programs to potential participants. The *registration* of participants with disabilities begins the *assessment* phase, determining individual needs and pref-

erences. Then the process turns to the ***building of individual supports*** which includes such things as the hiring and training of staff, the modification of teaching techniques and/or equipment, and the survey of facility accessibility. As the program begins, careful ***monitoring and communication*** occurs among all parties (participants, parents and staff) involved. Finally, as the program ends, all parties participate in ***evaluation***, and the cycle begins again.

FIGURE 1



Throughout the process, problems, oversights, and/or barriers can occur. Therefore, parents can take a crucial advocacy role in any or all of the seven phases. This process can identify why a particular advocacy approach is needed.

■ Organizational Structure: *Where and with Whom Advocacy is Done*

Figure 2 below, adapted from Terry's model on Authentic Leadership[2], represents a service agency in its entirety. It includes levels of staffing, various functions, and desired outcomes. Please refer back to this figure periodically to understand the presentation that follows.

FIGURE 2

Each level of the organization embodies different roles and responsibilities in terms of the direction, actions, and success of the organization's programs. Board members, administrators, and funders work directly on agency philosophy and mission and set the direction of the agency's actions. Managers, department heads, and supervisors work at the decision-mak-

ing (*power* level), and the policy implementation and procedure (*structural* level). Front-line staff use agency structures and resources to carry out the program, achieving success or experiencing failure. Throughout the inclusion delivery system, professionals representing these different levels interact with each other and all play important parts in the success or failure of the whole system.

In the initial phase of budgeting and planning, the higher echelons of leadership (board-council members, administrators, and funders) are involved in determining the *direction* and *outcomes* of the program. After the direction is set, the managers (department heads, program directors, and supervisors) use their power to create the structures (registration, assessment, support building, monitoring/communication, and evaluation processes) and determine the resources (staffing, equipment, and money) to be used. Finally, on-line staff implement the policies and procedures and use the resources (information, equipment, and facilities) to deliver the programs to the participants and their parents.

Knowing these roles and responsibilities and clarifying who has the power to make decisions, allows the parent advocate to prepare and launch a positive advocacy effort. The key to effective advocacy is to:

- Approach the inclusion delivery process at the appropriate organizational level, which is above where the problem is occurring;
- Identify the person to whom the case should be presented; *and*
- Present the case clearly, directly, and in a positive tone.

■ Collaborative Advocacy: *How it's Done*

As said earlier, our goal is not to stimulate adversarial relationships; we wish to focus instead on the participation of all levels in the organization to determine the direction, actions, and success of inclusive recreation programs. Parents should carefully identify the problem or issue and request a solution at the lowest appropriate level of the organization first. This is the level at which the problem has occurred. If a satisfactory change is not provided, however, the parent advocate should *approach the people in the organization at the next higher level.* It is the staff at the level *above* the problem who have the responsibility and the power to make changes, create the change-making processes, and gather the means to make things work.

One of the most consistently used rationales for denying access to an inclusive program is that the on-line staff do not know how to create inclusionary programming and/or do not have the resources to make inclusion happen "safely" or "successfully" for everyone. If we refer back to the organizational structure model for a moment, the on-line staff are *not* the group responsible for creating the inclusion policies and plans, or for obtaining the resources to implement the program – the managerial level is! So the first advocacy request for new structures and/or resources should go to the program manager, the *next level up.*

If the managerial level continues to create barriers, such as insisting that the participant with a disability provide his or her own supports (which is contrary to the intent embodied within the Americans with Disabilities Act), advocates need to move their efforts to the *next higher level,* the leadership level. Organizations which are resistant to including people with disabilities have often not had a clear directive from their top leadership personnel concerning each agency's inclusion direction, principles, and mission. It is important to remember that boards, councils, and funders have the power to set the direction for the whole organization and to encourage the leadership to make a clear mandate for inclusion.

Parent advocates should clearly and carefully present their issue to the appropriate staff person at each level and ask if he or she has the power to resolve the issue. If that person does

not, then the parent advocate should ask who does and move the advocacy effort to that next level, being mindful, however, that the initiating parents and participants will have to come back and work with that management and on-line staff member when final decisions are made. Hence parents should try to control their anger, and to not let a powerless on-line staff person "have it." He or she is only following the organization's chain of command, using resources that have been given. Instead, parents should inform the on-line staff person that they want to work with him or her to obtain the structures and resources needed to do a successful job of delivering recreation programs to everyone. Then they need to proceed to the appropriate organizational level to make their request.

■ The Organizational Response

The organization can respond in at least three ways: by initiating A) new or improved policies, B) projects, and/or C) development programs. Policies are guides through which organizational members are directed toward objectives. Projects are single operating structures, flexible in nature, that are highly adaptable but temporary, existing only for the life of the activity. Development programs are long-term in nature, potentially broad in activities, encompassing many projects and policies that are formulated in order to provide services which accomplish human service objectives.[3] Each of these responses takes varying amounts of time and resources to initiate and sustain. Hence advocates should recognize that it may take some time to get a new process rolling and allow the organization to work through its own channels and processes. However, a parent advocate can, and should, ask the manager or leader how long the response will take and if he or she can participate in the process by tracking the changes and reporting back to the manager as a customer of the service.

In closing, we suggest that people with disabilities and their supporters recognize that inclusion issues (issues of access and quality of service) are political issues, issues of deciding who receives what goods and services, and issues of the level of service quality that are offered by governments and organizations. Therefore, methods that have often been developed over the years to influence political decision-making are also appropriate for promoting inclusion. These include forming coalitions with like-minded people and organizations to present an organized constituent power-base; using the media; establishing appropriate and effective communication and relationships with the leaders of community, organization, and governmental entities; and lobbying and making legislative presentations. (See the *Foreword* for more detailed information on parents-as-advocates strategies.)

By adding these methods to the collaborative inclusion advocacy model presented, parents can become effective change agents for the inclusion of children and adults with disabilities in recreation programs. It really does take all parties working together to create fully inclusive, sustainable programs.

Building Relationships and Friendships through Recreation

LINDA A. HEYNE

Whether our relationships include school or work friendships, acquaintances, or lifelong social alliances, each personal connection adds a special dimension to our lives. To enhance the family and – in the broader context of family – the community, inclusive recreation can play a vital role in encouraging and supporting interpersonal connections for children and youth with disabilities. In fact, recreation settings have been identified as ideal environments in which to promote socialization and relationships among youngsters with diverse abilities.[1] When participating in recreation activities, differences in abilities are often minimized in favor of enjoyment, play, and camaraderie. Recreation activities also provide multiple opportunities for children with and without disabilities to meet, get to know each other, learn to get along, enjoy each other's company, and share mutual interests.

This article emphasizes the value of interpersonal relationships throughout the lifespan and, in particular, the necessity of building relationships for children and youth with disabilities in order to realize this value. Additionally, it identifies barriers to forming relationships and discusses ways in which recreation activities can be utilized to remove these barriers through facilitating interaction and supporting relationships between youngsters with and without disabilities.

The Importance of Interrelationships throughout the Lifespan

No matter what one's age may be, positive relationships and friendships play a significant role in one's quality of life. In childhood, peer relationships allow children to share affection, support, companionship, and assistance. Children learn vital life skills from each other that cannot be learned from adults. Through peer contact, children learn subtle social interactions such as how to communicate effectively, engage others in activities, be tactful, and deal with conflict. They learn to negotiate giving to others and receiving back from them. Eventually, peer interaction helps children separate from parents and develop independence. Relationships allow children to compare themselves meaningfully to others which, in turn, contributes to their sense of self, their identities, and their awareness of social realities. Childhood friendships also act as a buffer for conflict that might occur within the family, relieving feelings of isolation that may result.[2,3]

Through interpersonal relationships, children learn to assert themselves and to develop social skills that contribute to successful personal and work relationships later in life. The development of relationships in childhood has been deemed so essential to the maturation, health, and happiness of children that it has been called "one of the most important accomplishments of early childhood."[4]

During adolescence, same-sex relationships are particularly crucial as issues of independence and the formation of identity are explored. Teens tend to choose friends who are the same gender and are similar in age, background, and interests. Through their relationships, adolescents typically learn to express their feelings through intense closeness and emotional sharing. During the teen years, the value of adjusting one's behavior to meet the mutual needs of the relationship is also usually learned.[5]

The interpersonal skills learned in childhood and adolescence culminate in the expression of adult relationships. Adult relationships and friendships may take many forms. Relationships may be with *acquaintances,* people who we know by name or face due to the accidental ties of place or time. Our ties might be to *neighbors,* people who live nearby and with whom mutual help and protection are exchanged. We may come to know people we might call *confederates,* those with whom an enterprise or act is shared. We may share our free time with *pals,* people whose interaction revolves primarily around a mutual activity rather than conversation. Our connections might be with *close kin,* those who are related to us through family or extended family ties. Relationships may be with *co-workers,* people with whom we work and who may also become our friends. Finally, interactions might develop with close *friends,* people who become our intimates, our soul-mates.[6] Adult relationships anchor us in many life-affirming ways by giving us opportunities to talk about ourselves, to receive physical assistance, to gain emotional support and assurance of our personal worth, to help others, and to give us a sense of belonging.[7] In adult personal relationships, as well as childhood and adolescent relationships, there are definitive elements such as reciprocity, mutuality, self-disclosure, shared leisure experience, and an expectation that the relationship will endure.

■ The Importance of Relationship for Children and Youth with Disabilities

In recent years, evidence has been accumulating that demonstrates how a lack of relationship can jeopardize our mental, emotional, and physical well-being. Many believe that loneliness poses as serious a threat to emotional and physical health as does disease. For example, a loss of friends can result in depression, which can in turn weaken the will to live. Disturbance in relationship, it has been noted, is often the first link in a chain of events that leads to reduced self-esteem, emotional maladjustment, diminished physical health, an inability to resist disease, and even fatal illness.[7,8]

The importance of relationship for people with disabilities has also received some – though not enough – attention. People with disabilities have traditionally been stigmatized as undervalued members of society, and consequently have often been separated physically from other members of society. The deeper the rejection experienced and the wider the physical separation, the more discontinuity a person feels in social relationships and physical surroundings.[9] People with disabilities tend to have far fewer relationships than people who do not have disabilities. When relationships do exist, they tend to be with family members, other people with disabilities, or people who provide them with a service (such as a teacher, physical therapist or other health professional, therapeutic recreation specialist, or social worker) – not with peers without disabilities.[10] The anthropologist Robert Edgerton reported that adults with mental retardation who had been released from institutions but ex-

pected to live independently had to have a person nearby who was described as a "benefactor" in order to handle the ordinary problems of life. Without a benefactor, recidivism became a strong likelihood.[11]

Parents of youngsters with disabilities have expressed much concern about and support for their children developing relationships with peers without disabilities. In a study that tracked the formation of relationships and friendships of elementary-age children with disabilities over a two-year period, parents were interviewed about why they believed these relationships were so vital. Parents thought peer relationships were important for teaching their children appropriate play and social skills such as listening to others, waiting in line, taking turns, and paying attention to what was happening around them. They thought participation in recreation activities could help their children learn the give-and-take of social interactions. By participating in the same games and activities as peers without disabilities, their children could not only learn these activities but experience what it would feel like to belong to a group. Parents also felt relationships were important for their children to have for the same reasons that parents of children without disabilities do. As one parent put it, "They need someone they can be themselves with, hang out with, share their secrets with – someone to ask how things are going, and encourage and challenge them."[12]

When parents were asked about their hopes and dreams for their children with disabilities, they expressed a hope that peer relationships would reduce their children's tendencies to become over-dependent on adults. They hoped that, as they made friends with other children, they could look to them – rather than to adults – to meet their social and physical needs. Parents also hoped that their children would develop one or two close friendships and, in having experienced friendship, would retain the skills and confidence to make friends throughout life. (See *Family Focus Groups in the Dowling School Friendship Program*, page 35, for a full description of this study.)

■ Barriers to Relationship

Inclusive recreation implies not only *physical placement* in regular community recreation but *social belonging* as well. Many real barriers to both the physical and social inclusion of people with disabilities have been identified, however. For example, barriers exist when community recreation agencies have difficulty identifying participant needs and preferences, have staff that are not trained to meet the needs of people with disabilities, have negative attitudes about people with disabilities, offer segregated rather than inclusive program offerings, or are not architecturally or programmatically accessible.[13] For children in particular, barriers to relationship result when families' busy schedules prevent parents from arranging times to get together with other families to encourage their children's friendships.[12] For young adults, the most commonly reported obstacle to social and recreation inclusion is the lack of a companion, friend, or advocate to accompany the person with a disability to a community activity.[14] Despite these obstacles, recreation professionals have been working to redesign recreation activities and environments that do promote interpersonal interaction and relationship between people with and without disabilities.

■ Using Recreation Activities to Build Relationship

Friendship has been defined as "a heart-flooding feeling that can happen to any two people who are caught up in the act of being themselves, together, and who like what they see."[6] In order for two people – such as a youngster with a disability and a youngster without a disability – to have such an experience, however, they must have opportunities to meet each

other, interact positively, and learn about each other. As stated earlier, inclusive recreation activities provide just such an optimal setting for these exchanges to take place. Even so, recreation activities in and of themselves, do not create relationship. Specific, conscious efforts must be made to create recreation environments and teach the skills to utilize these environments through which relationship can blossom and develop.[15] Here are some of the strategies that recreation professionals and others have used to create the environments and develop the skills that nurture inclusive relationships:

- **Educate peers without disabilities about people with disabilities:** Education can break down stereotypes, answer children's questions about disabilities and people who have them, and reinforce positive images of people with disabilities.
- **Use cooperative learning arrangements:** Activities that are structured to promote teamwork, cooperation, mutuality, and working toward a common goal recognize each participant's contribution to the joint effort (see *Paving the Road to Inclusion with Cooperation* on page 27).
- **Teach group leaders to structure activities and interactions to promote inclusion:** A group leader can be a vital catalyst for inclusion by setting a tone of acceptance, modeling positive interactions toward participants with disabilities, setting up play situations in which children can readily interact, and keeping activities child-centered.[12, 16]
- **Adapt activities to maximize independent functioning:** Modifying rules, procedures, or play materials can enable children with disabilities to participate fully in activities.
- **Provide social skills instruction for children with disabilities:** Through role playing and problem-solving, social skills instruction can teach children such skills as how to initiate and maintain conversations, establish compatibility, offer support and appropriate comments, and resolve conflicts.
- **Plan collaboratively to support children's relationships:** Through such processes as Circle of Friends,[17] Personal Futures Planning,[18] the McGill Action Planning System (MAPS),[19] Planning Alternative Tomorrows with Hope (PATH),[20] or focus groups,[12] important people in a child's life can work together to build a vision that supports the nurturance of relationships.

Through these means, and by giving children with mixed abilities opportunities to interact together in supported play situations, recreation activities can contribute immeasurably to building relationship and friendship.

Paving the Road to Inclusion with Cooperation

JOHN E. RYNDERS

Rugged individualism, as personified in Hollywood portrayals of the Western cowboy, served a strong need of our society in the 1800s. For the pioneers of that period, to stake out a piece of land, build a sod hut on it, and hold out against prairie fire, the threat of starvation, and crushing loneliness did, indeed, require rugged individualism. But pioneering life often also required some *cooperative* efforts – barn raisings, for example – which are glossed over in popularized Western movies.

Hollywood's fascination with rugged individualism in the pioneering period was replaced with the glamorization of competition in films about the Industrial Revolution, personified in movie portrayals of the steel mill moguls' power-grabbing tactics. Retaining some elements of the cowboy's rugged individualism, the emphasis shifted strongly toward "punching out" other moguls rather than "cow punching."

In their proper place, both individualism and competition are valuable traits. They have had, and continue to have, importance in our form of democracy which is egalitarian and entrepreneurial at the same time. They have been particularly useful at times of societal threat such as occurred during World War II. But, as professors Roger Johnson and David Johnson of the University of Minnesota point out,[1] individualism and competition (especially competition) have been over-popularized, not only in society at large, but in schools and other youth-serving agencies where they can act to the detriment of promoting important societal as well as schooling values. To illustrate this threat, and to show how to avoid it, let us look at an example of a recreation activity – canoeing – that has been structured for competition, individualism, and cooperation.[2]

■ Alternative Recreation Structures

Competitive structuring in its traditional application leads to *one* person in a group winning while all the other members lose. If it is used in a group where one or more of the members have task-related disabilities, it will be highly likely that the participants with those disabilities will "come in last." An example of competitive structuring from the world of camping would be to have five children, some of whom have movement disabilities, line up at the edge of a lake for a canoe race. Each has a canoe and a paddle. The camp director tells them that the person who reaches the other side of the lake first will win a miniature canoe paddle. It doesn't take much imagination to

realize that the children who have poor coordination and low muscle tone, as is not uncommon among persons with disabilities, have little chance of winning. Informed program leaders would not use a competitive goal structure in real life in this manner of course, but would rely on one or both of the following structures instead.

In an *individualistically structured* situation, each member of a group works to improve his or her previous performance. Using the canoe example, the adult leader lines up members of the group on the shore of the lake and tells them that last week when they paddled across the lake each person's crossing time was recorded. Then the leader says that *each* person will win a miniature canoe paddle if he or she improves his or her time, even if the improvement is very small. Potentially, every member of the group, including members with disabilities, can win a prize for improvement if the targets for improved performance are not set too high or are not inappropriately matched with a disability condition.

Cooperatively structured activities are very helpful in many types of integrated settings, particularly if peer socialization is the goal. By its very nature, a cooperative learning structure (if handled properly) creates an interdependence rather than independence because the group's attainment of an objective with everyone contributing is the quality that determines winning. Using the canoe illustration, the adult leader has five children climb into a large canoe, gives each a paddle, and tells them that they should each paddle as well as they can and that they will all win a prize if they work together to keep the canoe inside some floating markers (placed in such as way that perfect paddling isn't required). The adult leader will need to paddle alongside to determine that everyone is paddling and is encouraging, reinforcing, and assisting one another.

In sum, of the three, the cooperative structure will work better to promote positive social interactions between participants with and without disabilities. Why? Because, in a competitive structure, the child is concentrating on paddling the fastest; he or she doesn't have time for socialization. Similarly, in an individualistic structure the child is concentrating on bettering his or her performance, again without incentive for socialization. In the cooperative structure, however, each person wants to support every person's effort in the group to achieve a common goal. This promotes positive social interactions such as encouragement, cheering, and pats on the back. Cooperative structuring is the best means to achieving successful inclusion from a socialization standpoint – but what if skill development is also a goal?

■ The Roles of Participants

It is important that the adult leader be clear about the desired role of nondisabled peers in interaction with peers who have disabilities. The leader must determine whether the peers without disabilities will be interacting as *tutors, companions,* or *both tutors and companions.* Each role has a different purpose and fits a slightly different overall goal. All three of the roles, however, fit well into a cooperative learning orientation.

The usual purpose of a *peer tutor* role is to have a peer without a disability teach a skill to a peer with a disability. The relationship of peers in a tutoring program can be thought of as "vertical," that is, the tutor is in charge. An example of a peer tutor program is where a twelve-year-old peer without disabilities works one-to-one on teaching canoe paddling skills to a six-year-old child with a disability. Later those skills will be useful for the child with a disability to have as he or she paddles cooperatively in the five-person canoe. A word of caution, however: The child with a disability should not always be involved in recreational activities as the one who receives "help." It is important for a child with a disability to experience a giving as well as a receiving role. Nor should the older nondisabled peer be cast into a role where he or she is expected to become parent-like.

The primary purpose of a *peer companion* program is to promote social interactions between a child with a disability and a child without a disability. To achieve this purpose, the peers should be approximately the same age, although it is okay, and even an advantage, if the child without a disability is one or two years older than his or her partner who has a disability. It is not usually desirable for the child with a disability to be older than the child without a disability; our research shows that this can create a socially awkward situation. The relationship between two people in a peer companionship program can be thought of as "horizontal," that is, a relatively equal, turn-taking relationship. A typical application of this arrangement is where two peers, one with a disability and one without, make a pizza together, taking turns putting on the ingredients, washing the dishes together, etc.

■ Tips for Successful Peer Companionship

Since most of the integrated programming we have done has emphasized *peer companionship* (socialization rather than task skill building) the following tips on peer companionship are provided for parents who are assuming the role of activity leader:

Tips for Parents to Use in Maintaining an Activity

- Check that all materials and a good working space are available for members of the group to work together.
- Make sure that materials and tools are laid out for safe and easy access.
- Check that the position of each participant with a disability is reasonably close to his or her partner.
- Adapt the activity to the ages and ability levels of participants, and particularly for the characteristics of participants with disabilities.
- Encourage cooperative interactions when they don't occur; reinforce cooperative interactions where they do occur.
- Redirect when a participant is off-task and step in if a situation is deteriorating.
- Say something pleasant to participants as the project ends.

Behaviors to Encourage in Nondisabled Peer Companions

Help Your Partner Get Started

- Use an attention-grabber such as, "Chris – See this nut shell? I can make a picture with it when I dip it in the paint."

Help Your Partner Feel Good about Doing an Activity with You

- Encourage your partner by saying things like, "I bet you can make a red picture with this nut shell."
- Reward success or partial success by saying things like, "Hey, Chris, that was a good try," or "I like your picture."

Help Your Partner Do Things as Independently as Possible

If the steps in a project are obvious and within your partner's capabilities, invite your partner to go ahead on his or her own. Then, if assistance is required, do the following:

- Verbally instruct your partner by saying something like, "Chris, dip the shell in the paint and press it onto the paper."

- If verbal instructions haven't worked, you can verbally instruct and demonstrate the steps: "Chris, watch me dip this shell in the paint and press it into the paper. See?" Demonstrate the steps and reposition the materials and say something like, "Now you try it."
- If this still hasn't worked, you may try verbal instructions matched with physical guidance: "Chris, let's do this printing together." Gently nudge your partner's arm toward the materials. If your partner doesn't continue on his or her own, then gently take your partner's hand and do the complete movement. Reposition the materials and have him or her try it alone. It's important to remember when using this type of assistance that some people don't like to be touched: if you experience a negative reaction, then stay with verbal instruction paired with demonstration.

Help Your Partner Handle Frustration and Recover from Failure

- Respond to accidents calmly; reposition materials for another try.
- Correct your partner gently if he or she misbehaves toward you by saying "no" calmly but firmly. Provide a second chance. If misbehavior continues, ask the adult leader for assistance. Don't try to discipline your partner: that's the role of an adult leader or parent.

Help Your Partner to a Good Activity Ending

- Say pleasant things about the project and interactions as materials are being put away.
- Share clean-up responsibilities.
- End the interaction by saying or doing something pleasant.

■ Conclusion

Today, collaborative social movements such as Take Back the Night, along with environmental movements like Greenpeace, are moving – sometimes *pushing* – society toward a more *cooperative* mentality. As the cooperative spirit grows, people with and without disabilities should benefit increasingly. In this process, communities, families who reside in them, and individuals with disabilities who recreate, work, and live productively in the community should all be better off. In the next century, perhaps all of society will come to realize fully that the road to inclusion success is "paved with cooperation."

Emphasizing Abilities Across the Lifespan — Why Bother?

CARLA E. S. TABOURNE
JOHN E. RYNDERS

Perhaps because the United States is a wealthy nation, we have developed a "disposable" mind-set – we waste our resources. In our competitive marketplace, we value the fastest, brightest, most stylish version of everything. And, when a new model emerges, we toss away the older one: it isn't worth the time nor the money to fix, refill, or restore. Unfortunately, we often transfer this "disposable" attitude from products to people.

In humanity's early history, individuals were cast aside who could not contribute to the growing or obtaining of items necessary for the society to survive. Later, society felt that it needed the best and brightest in control and in power. Rich societies hid its weaker members away but provided basic care for them. However, in doing so everyone lost out because those who were ignored were unrealized resources for the society. Slowly, growing out of an economic need to contain costs and a social demand for equal rights to be included, marginalized people are being reassessed for their potential value as contributing members of society.

This means that for a variety of reasons we need to, or are being forced to, consider humans of all abilities as *developmental capital* (a term proposed by Dr. Evelyn Deno, a former faculty member at the University of Minnesota) rather than as "surplus populations." Contributing to society is taking on a new meaning, one that is less concerned with the quantity of products people can produce and more with the quality of life they can affect.

At least three developments should be factored into a new equation for American life: *mechanization, communication,* and *increased life expectancy.* First, the move from industrialization to mechanization leads to a reduced, more educated work force. As automation revolutionizes industry, the skilled, factory-based work force continues to shrink, while service industries continue to grow. This calls for either retraining workers or adding large numbers of people to the surplus list.

Second, during the latter half of the twentieth century, America has entered a new "communication" era. We now see, hear, and have access to more information than was ever thought possible. Live media coverage of events makes the world seem smaller; we are able to actually witness history as it is made. New occupations that previously did not exist, and that do not require physical strength, allow for a new work force and new workers. Nearly half of this work force are women; a much smaller percent are people with disabilities.

A third factor is the increased lifespan for most Americans resulting from reduced infant mortality, im-

proved nutrition, and advances in health care. People have greater access to nutritious food than ever before in our history. The young who are born prematurely or people who would previously have died from infection survive. People who benefit from early diagnosis and treatment or use biomechanical apparatus live. The society as a whole is living longer, well beyond the retirement years as defined by the traditional SSI standard. One can now anticipate living almost twenty years beyond the formal working years. Twenty years to do what? Persons of advanced years are likely to answer these questions in very different ways depending on their age, interests, health, and wealth.

■ Persons of Advanced Years

Americans born in the 1930s, who are now considered "young old" (over 60) are, in most cases, significantly different from the next older cohort (ages 70–79). They know the effects of war, but few have fought in one. They know of wholesale economic depression, though only through the eyes of their parents. Young-older, white, middle class persons are more likely to have incorporated leisure activities into their lives than to have deferred them until retirement. They may share the view of traditional family life of their parents but while they respect authority they also recognize that they have a voice in many decisions affecting them. The picture is significantly different for the contemporary middle-older-aged adult (ages 70–79), and even more distinct are those who are currently over eighty years of age.

Chronological age is not the sole determinant of aging. Self-concept and social status are two equally important barometers of aging. One's sense of identity, self-esteem, and body image are critical factors in the aging process.[1] Concomitantly, social status assigned by others reflects how much control or power a person is believed to be able to exert on others. The perception of control is related to one's internal or external locus of control.[2] Psychologists and sociologists report, in their studies of locus of control in older persons, that elderly persons who are self-determined and involved in living and who feel that they have some power and control, derive greater satisfaction from life. Likewise people who feel supported from close relationships with family and friends may experience an enhanced internal center of control provided that the support or assistance has some degree of reciprocity. If the older person begins to view this assistance as coming from fate, outside change, or from other people who are powerful, the locus of control will be external. Extremes of either personality characteristic or locus of control are likely to hinder the ability of older persons to cope with rapid changes in their lives or in society as a whole. An inability to adjust to these changes may present a picture of inflexibility which might quickly lead to erosion of status.

Misinformation can also lead to loss of status for older persons. There is a misperception (by older adults and society as a whole) that all needed services are well covered by Medicare or Medicaid for people over sixty-five. Nothing could be further from the truth. These programs, in fact, do not cover many of the most frequently required services (e.g., dental care, drugs and medicines, eye glasses and hearing aids, custodial care in the home). These very items, if covered, would increase the possibility of prolonged independence, active family membership, and contribution to society. Perhaps it is this potential for contribution that is unclear in the eyes of the younger, nondisabled members of society. They may ask, "What is the contribution of older Americans to society?" The answer to this question might be revealed through their own process of discovering ways to contribute. Maybe their contribution to humankind is realized in part in the effort of nondisabled persons to identify the contributions of all people. Perhaps the answer lies in the fact that elderly people bring a lifetime of experience to their community if tapped properly – experience that when paired with greater control of discretionary time, can lead to valuable volunteer efforts.

■ Persons with Developmental Disabilities

The need for regarding persons with developmental disabilities as "developmental capital" is an idea created, as far as we can tell, by Dr. Evelyn Deno of the University of Minnesota about twenty years ago. The idea behind her premise was that society, because of socio-economic and other factors, would eventually come to *need* people with developmental disabilities, particularly to staff a burgeoning number of service-type occupational slots due to a diminishing number of non-disabled people able to fill the slots. Later, society would come to *value* the contributions of people with disabilities as employers began to realize that they could become some of their best employees, given proper training and support. The shift from an attitude reflective of *need* or *obligation* to one of *positive valuing*, requires that excellent training be provided since the person with a disability must be able to overcome society's low general expectation by showing "conspicuous success,"[3] success in this case, in the form of employee excellence.

Gleidman and Roth[3] describe this transforming process as follows:

> *In nearly all instances the cripple* [person with a physical disability], *the blind man, even the adult who admits to a reading disability, must contend with* [society's] *belief that, until proven otherwise, the handicap renders him less capable than an able-bodied person of similar age, sex, and social background. Overcoming this presumption of inferiority is not impossible, but it may require a very special kind of sociological tour de force. Defined by society as a conspicuous failure, one way out is open to all: the possessor of a negative handicap can always prove that he is the exception to the general rule* if *he can achieve conspicuous success in some area of life.* (p. 28)

At first glance, society's laying an obligation to show conspicuous success on people with disabilities looks patently unfair, and in many ways it is. But it also has positive implications for us as parents and recreation providers who are interested in inclusion. First of all, we can assist the person who has a disability to select inclusive recreation activities that compliment the person's strengths, not weaknesses. Second, activities within the person's area of relative strength can be encouraged that have a lower threshold for success. These will be easier areas in which to exhibit success. For instance, if the person has an interest in fishing with nondisabled peers, and a good capability in coordinated upper limb movement, then training the person to do spin casting for pan fish (easy to do, easy to catch) instead of fly fishing for trout (hard to do, hard to catch) should be explored. Third, the inclusive environmental context itself can be influenced so as to become more tolerant of less-than-perfect performance on the part of persons with disabilities. For instance, preparing inclusive groups to collaborate, and then structuring tasks for cooperative outcomes can produce a socially positive (and more tolerant) atmosphere. Similarly, adapting activities to be more accommodative in the first place can be helpful, and analyzing the environment to discover "trouble spots" for the person with disabilities, and then avoid those spots can mitigate lowered proficiency in a norm-referenced cooperative atmosphere. Also, giving nondisabled participants an improved perspective on the unique qualities that people with disabilities bring to an inclusive situation can be helpful, especially when paired with introspective learning opportunities that allow nondisabled participants to see themselves in a more humane, less-than-perfect, manner. All of these context-improving techniques are described in this report.

In a few words, the answer to the question posed in the title – *Why bother?* – is that the person who is elderly or who has a disability is advantaged when society "bothers." Furthermore, society is itself improved substantially in the "bothering" process.

PART THREE

Illustrations of Inclusive Recreation

Family Focus Groups in the Dowling School Friendship Program

LINDA A. HEYNE

Friendships have the potential to serve numerous life-affirming functions in a child's life. Through interacting with their peers, children experience companionship, affection, support, a sense of belonging, and an enhanced self-esteem through feeling valued by others. They test out the give-and-take of social interactions, gain an awareness of their identities, learn the limits of their independence, and negotiate how to be part of a group.[1,2]

Friendships and social relationships are essential for all children but, unfortunately, children with disabilities often lack the emotional and physical supports needed to make friends.[3] Even though children with disabilities are increasingly included in regular education classrooms, they often work on individualized assignments different from those of most of their classmates. After school, they typically take a long bus ride home to neighborhoods that are also different from their classmates. Consequently, few opportunities exist for children with and without disabilities to play together, get to know each other, and become friends.

■ Program Beginnings

The Dowling School Friendship Program was initiated to try to understand the complexities of relationships and friendships between children with and without disabilities. The participants in this two-year program included twenty-eight families whose children attended a Minneapolis public elementary school called the Dowling Urban Environmental Learning Center – the "Dowling School." Five families included a child with a disability and twenty-three families included only children without disabilities.

Throughout the program, each child with a disability was matched with two to five classmates without disabilities and invited to participate together in a variety of recreational activities. Matches were made based on children's preferences, parents' recommendations, and teachers' suggestions based on observation of classroom dynamics. Recreational activities took place during lunchtime at school, after school, on school release days, and occasionally on week-nights and weekends. Activities were generally held on the school premises and included such offerings as art, Girl Scouts, theater, computer, basketball, Native American culture, T-shirt painting, pottery, nature, kite-making, and plant care. When a parent or child took the initiative to make the

necessary arrangements, activities also took place in families' homes and neighborhoods. These informal, less structured activities included cookie baking, birthday parties, playing video games, roller-skating, eating pizza, as well as other spontaneous get-togethers.

Throughout the program, the children and their parents regularly participated in one-to-one interviews about the children's relationships. Additionally, families met in *family focus groups*, which are described in detail below, to discuss the children's friendships.

■ Family Focus Groups

A *focus group* is defined as a guided group discussion that brings people together to freely share their perspectives on a given topic without judgment or censorship.[4] Focus groups can be a highly effective tool for gathering information, assessing needs, and promoting collaboration. In focus groups, people who share a common concern – but who typically represent diverse viewpoints – come together to express opinions, discuss issues, exchange ideas, and generate solutions.

In the Dowling School Friendship Program, family focus groups met three to four times a year to address questions related to the children's relationships and friendships. These questions arose from the particular situation at Dowling School, a situation similar to that experienced by many other communities across the country: the long-standing history of segregation of students with disabilities, the recent physical inclusion of students with disabilities in regular education classrooms, the unanticipated lack of social interaction and friendships that occurred between students with and without disabilities, and the lack of opportunities available to children without disabilities to learn about children with disabilities. In talking with Dowling School parents, children, and school staff, three fundamental questions took shape:

- What is the *nature* of relationships and friendships between children with and without disabilities?
- What *barriers* prevent friendships between children with and without disabilities from occurring?
- What *strategies* can be used to encourage friendships between children with and without disabilities across school, home, and neighborhood settings?

Family Focus Group Participants

Each family focus group included a child with a disability and his or her family members, two to five classmates without disabilities and their family members, school staff, recreation staff, and program staff. (Typically, heterogeneous, rather than homogeneous, groups of individuals are sought for focus groups in order to gain information from a range of opinions and experiences.) Dowling School family focus groups involved families which represented a spectrum of family member compositions, ethnic and cultural backgrounds, socioeconomic statuses, and children's grades and ages. To complement this diversity, family focus groups had a common unifying interest: friendship development between children with and without disabilities.

Locations

At the onset of the Dowling School Friendship Program, family focus groups met at the school, a common point of reference for all the group members. Later, as group members became more familiar with each other, suggestions were made to meet at neighborhood recreation centers and invitations were extended to gather in people's homes.

Meeting at community recreation centers proved advantageous for several reasons. Fami-

lies who had no previous exposure to these facilities could locate and explore them, learn about recreation programs for their children, and examine the facilities for programmatic and architectural accessibility. Meeting in families' homes was also beneficial: the atmosphere was informal and warm, promoting greater self-disclosure and ease among group members. Families could connect personally and assess whether and how relationships between family members might develop. When the focus group was held at the home of a child with a disability, a parent of a nondisabled child could observe the child with a disability on his or her own "turf," watch how the child interacted with others and the environment, and learn from the example of the child's parent how to meet the child's needs. In all cases, wherever family focus groups met, the selection of meeting sites was decided collectively by the focus group participants themselves.

Scheduling

Because families led extremely active lives, meetings were arranged several weeks in advance and families' schedules were coordinated so that as many group members as possible could attend. Meetings were held at convenient times (usually in the early evening hours) and at nearby locations. Sometimes, families were available only over the dinner hour, so they met for potluck suppers. Because focus group members were handpicked and ongoing input from all the participants was important, project staff reached out to families in an individual and personal way to encourage their attendance. To set up meetings, phone calls were made to determine when and where families would be able to attend meetings. Flyers with information about the meeting particulars were developed and mailed to families. Additionally, follow-up reminder phone calls were made to the families by program staff the day before each focus group.

Format of Meetings

In talking with the families involved in the Dowling School Friendship Program, it soon became apparent that in order for families to work together in focus groups, they first needed to get to know each other. If families were to attend meetings, given the diverse activities and responsibilities competing for their attention, meetings would need to be interesting, enjoyable, and personally beneficial. Consequently, meetings resembled social gatherings as much as possible – that is, friendly, personable, festive, and fun. The task of addressing questions related to the children's friendships was introduced as people were ready to tackle it. Eventually, two family focus group objectives evolved: first, for families to become acquainted and, second, for group members to work together to discuss questions about friendship.

The format for meetings reflected the extent to which families knew each other. That is, in some groups, only two or three parents knew each other; in other groups, none of the parents knew each other; and in one group, families lived in the same neighborhood and parents had already been initiating informal connections between the children for years. Therefore, if families were well-connected, group members were more able to focus on the discussion; if families were not well-connected, the tone of the meeting was more social in nature. Given the considerations of family connectedness and maintaining a social atmosphere, meetings generally followed the format described below: while this format worked well at Dowling School, the structure of the focus group would need to be individually tailored to meet the needs of the specific community involved:

- **Informal Social Time:** The first fifteen or twenty minutes of a family focus group was spent engaged in informal social interactions. Besides allowing a grace period for latecomers, this social time provided an opportunity for group members to meet each other,

engage in light conversation, share information, and enjoy refreshments. Name tags were provided until group members knew each other by name.

- **Welcome and Introductory Remarks:** After everyone had arrived and people had opportunities to greet each other, the moderator welcomed the group members, introduced him- or herself, and invited the group members to introduce themselves. (As people became acquainted, these self-introductions were no longer necessary.) Next, the meeting agenda was reviewed. For the program at Dowling School, the moderator was typically a project staff member from the University of Minnesota. This role could just as easily be filled by a parent, teacher, recreation program leader, school social worker, inclusion facilitator, or any other interested person from an agency or the community. This portion of the meeting required between five and ten minutes.
- **Program Update:** For the next ten to fifteen minutes, an update of the Dowling School Friendship Program, particularly as it related to the group members who were present, was provided. This update included information about the children's participation in recreation activities and any other general program announcements. Updates focused on the children's involvement in programs; used slides and photographs to show children interacting and playing together; and displayed "products," such as art or craft projects, that the children had made. The moderator usually led the update, with supplementary reports provided by parents, recreation program leaders, and classroom teachers.
- **Children Participate in Cooperative Activities While Parents Discuss Friendship Questions:** After the update, the children were escorted to a separate room – a gym, multi-purpose room, or family room – to play together in cooperative activities such as parachute games, cookie decorating, or a variety of "New Games." While children participated in activities, parents, school staff, and recreation staff discussed the issues regarding the children's friendships. Depending on the group dynamics, the discussions varied from being led by the moderator who supplied questions to resembling a group conversation. Although the moderator was prepared with specific questions for discussion, the format was kept flexible so that group members felt free to introduce and discuss new information, concerns, or questions. Discussions usually lasted about thirty minutes. At the end of the discussion, group members were asked to complete a one-page evaluation form which asked questions about participants' expectations, how well those expectations were met, the effectiveness of the family focus group, and friendship development for the children.
- **Family Recreation Activity and Social Time:** After the focus group discussion was brought to a close, parents and other group members were given the option to join the children in a cooperative activity appropriate for all ages – such as volleyball, a parachute game, or a craft activity – and/or to visit informally with the other focus group members. During this time, group members had opportunities to continue to become acquainted, share comments and experiences, exchange telephone numbers and addresses, or make plans for the next get-together.

All-family Focus Groups

At the beginning and end of each year of the Dowling School Friendship Program, each of the five family focus groups were brought together for an "All-Family Focus Group." These meetings were intended to provide introductory or closure information about the program, to bring together a larger group of people interested in friendship development to share experiences, to strengthen the ties between group members, to thank the group members for participating, and to "showcase" the children's participation in the program.

■ Program Outcomes

Over the two years that families met in focus groups, many thoughtful insights and impressions were gathered from the parents and their children. Through the family focus group process, families had opportunities to meet each other, to develop relationships with each other, and to discuss the issues and solve some of the problems impeding friendship development between children with and without disabilities.

Identifying Barriers to Developing Friendships

Focus group participants identified several barriers that stood in the way of the children with and without disabilities making friends. It was rare that any single obstacle by itself prevented a friendship from developing; typically, several barriers operated simultaneously. The barriers listed below are presented in order from those most frequently reported to those least frequently reported:

- **Families' busy schedules:** With the day-to-day responsibilities of maintaining a household, caring for children, and earning a living, as well as the constantly competing demands on a family's time, most families led very active lives. Because of their busy schedules, it was difficult for parents to find time to actively seek ways to encourage the children's friendships.
- **Lack of knowledge about recreation's role:** Focus group members were not always aware of the important role recreation can play to promote positive interactions between play partners, encourage communication and friendship, and teach leisure skills and games.
- **Lack of communication and social skills:** Friendship development was impeded if children lacked important social and communication skills such as how to join a group, greet other children, take turns, share materials, "hang out" with other kids, or know when to speak and when to listen.
- **Distance between homes:** If children did not live within about three blocks of each other – that is, if a parent needed to drive a child to another neighborhood in order for children to play together – children seldom saw each other outside the school day.
- **Families were not acquainted or did not "click":** Families reported that they had too few opportunities to meet each other. Consequently, it was difficult to establish the level of liking and trust that were necessary for parents to feel comfortable leaving their children in the care of others.
- **Lack of transportation:** If one of the families did not own a van, if public transportation was not accessible and available at convenient times, or if a wheelchair did not fit into a personal car, children with physical disabilities often had no means to meet friends at their homes or in their neighborhoods.
- **Need for information about disabilities:** For children without disabilities to accept children with disabilities, they needed accurate information about disabilities and opportunities to interact with children with disabilities. Parents of children with disabilities also needed accurate information in order to feel confident about inviting children with disabilities into their homes.

Recommendations for Encouraging Friendship

Participants in the family focus groups agreed that families, school personnel, and community recreation staff can all play significant roles to encourage friendship between children with and without disabilities. Their recommendations for promoting friendship across home,

school, and neighborhood settings are presented below. Some of the positive ways that *families* can influence friendship development included:

- **Make friendship development a family priority:** If friendships are to develop and thrive between children with varying abilities, families recognized that friendship development needed to become a top family priority.
- **Become acquainted with other families:** Parents suggested that they needed to get to know other families in their neighborhoods who had same-age children through attending school functions and events at community recreation centers.
- **Schedule children's times together and invite children into homes and on outings:** Parents recognized that their children needed frequent and ongoing opportunities to play together and interact. To make certain these opportunities occurred, parents felt they needed to take an active role – through exchanging telephone numbers and addresses, and taking the initiative to extend invitations and arrange for transportation.
- **Learn about individual needs of children:** To feel comfortable assuming responsibility for children with disabilities in their homes, parents of nondisabled children expressed that they needed to learn about the individual needs (behavioral, communication, physical handling, mobility) of children and how to meet them.
- **Discuss and support children's friendships at home:** To support the children's relationships, parents thought they needed to talk about their children's friendships at home, as well as learn ways to arrange for cooperative play and teach friendship skills.
- **Learn about community recreation resources:** As a means of identifying opportunities for children with and without disabilities to share experiences in their neighborhoods, parents recognized the need to explore neighborhood recreation resources, such as parks, recreation centers, nature centers, and shopping malls.

The following strategies outline the ways in which focus group members believed *school staff* could support friendships during the school day:

- **Include social and recreation skills in curricula:** By giving opportunities for children to play and interact together during the school day, children can learn how to get along with and respect others, solve problems, make decisions, gain self-confidence, and build enduring relationships and friendships.
- **Assign friends to the same classrooms:** Because children tended to make friends with other children who were in their same classrooms, teachers were advised to pay special attention to the friendships that developed and make arrangements for the children to be in the same classroom from year to year.
- **Provide opportunities for families to become acquainted:** If children's friendships were to extend beyond the school day, families needed opportunities to meet each other, become acquainted, and mutually support the relationships.
- **Include friendship and recreation goals in IEPs:** Because recreation has been identified as a "related service" in several federal laws, parents and school staff can work together to include recreation and friendship goals in Individualized Education Plans (IEPs).
- **Train school staff on children's friendship:** Focus group members recommended that school personnel, whose training may have emphasized academic learning, also receive training on the importance of promoting social interaction, friendships, and recreational opportunities.

- **Offer disability awareness training to parents and children without disabilities:** To promote awareness and eliminate stereotypes about individuals with disabilities, schools could sponsor educational sessions about disabilities and people who have them.
- **Tell parents when friendships develop:** Because parents rarely have opportunities to observe their children during the school day, it was suggested that teachers inform parents of budding relationships so they can take an active role in nurturing them.

Lastly, focus group members offered the following recommendations for how *community recreation staff* can create opportunities for children with and without disabilities to meet, get acquainted, and become friends through participation in a variety of recreation activities:

- **Welcome all children in recreation programs:** Through agency mission statements, brochures, news releases, and other advertisements, recreation agencies can make a public statement that individuals with disabilities are welcome and will be served inclusively.
- **Ensure architectural and programmatic accessibility:** Community recreation staff should be certain that their facilities, parking lots, and playgrounds are physically accessible for individuals with disabilities. Additionally, participants who register for programs need assurance that their special needs will be met in those programs through adapting activities or equipment, providing one-to-one assistance, educating children without disabilities about disabilities, and managing behaviors.
- **Educate staff to meet individual needs:** In order for program leaders to feel qualified and confident to work with children with disabilities, community recreation agencies need to educate them about disability issues and strategies to facilitate inclusion.
- **Provide cooperative activities that promote positive peer interactions:** Community recreation staff may need to re-evaluate their programs to make certain there are ample opportunities for cooperation, social interaction, group learning goals, and relationship building.

Additional Benefits

In addition to the outcomes described above, several unforeseen benefits emerged from the focus groups:

- New avenues for regular communication were established between school personnel and families.
- Parents could observe their children with and without disabilities interacting and playing together, an opportunity that most parents had previously not experienced.
- Parents of children with disabilities could see, first-hand, their sons and daughters successfully interacting with other children. For those parents who had doubts whether their children could ever have friends, observing these interactions gave them hope that such friendships were possible. The visible proof of social interaction and friendships gave these parents higher expectations for friendship development for their children.
- The focus group discussions served as an eye-opening, educational experience for many of the parents of nondisabled children as they listened to the personal joys and struggles of parents of children with disabilities.
- The recognition that children without disabilities received for their involvement in the Dowling School Friendship Program reinforced their commitments to the relationships. After family focus groups took place, the children without disabilities appeared more interactive, involved, and easy-going in their relationships.

- Parents of children without disabilities experienced a sense of pride that their children had volunteered to participate in the program and admired their children for the skills of relating they had developed that they themselves did not possess.
- During the all-family focus groups, parents of children with disabilities were able to share with others in similar situations and, consequently, felt less alone in their endeavors to help their children make and keep friends.

■ Guidelines for Conducting Focus Groups

The following guidelines are offered for parents, school staff, and recreation agency personnel who are interested in organizing a family focus group related to friendship development or any other topic relevant to inclusive recreation. Richard Krueger's book *Focus Groups: A Practical Guide for Applied Research* is a useful resource for conducting focus groups.[4] This book provides many straightforward, easily applied tips for conducting effective focus groups.

Focus groups typically share some common characteristics. However, when applying this process to your own community's issues and concerns, it is important to keep in mind that the focus group process is also highly flexible and is intended to be adapted to particular needs and situations. Common characteristics of focus groups are listed below:

- **Participants share a common concern, need, or experience:** Participants may all use the same service, attend the same program, use the same product, be employed at the same workplace, or live in the same community. If the common concern is friendship development between children, key people in the children's lives – parents, siblings, classroom teachers, therapeutic recreation specialists, occupational or physical therapists, speech therapists, and social workers – may be included as focus group participants.
- **A warm, supportive, non-judgmental environment is provided:** An "open forum" is created that allows for free-flowing dialogue and the exchange of ideas.
- **Participants meet for a specific, well-defined purpose on a time-limited basis:** Each focus group member should clearly understand the purpose of the meeting. Typical focus group purposes might be to assess needs, identify problem areas, test recreational materials, brainstorm ideas, obtain feedback, and/or evaluate services.
- **Seven to ten participants are typically involved:** If fewer than seven individuals participate, one or two people tend to dominate the discussion; if more than ten individuals are involved, the group tends to fragment into smaller groups and side discussions.
- **Participants generally do not know each other:** Because participants usually have not met before, they are often willing to disclose impressions and opinions more freely. If the topic is friendship development, however, it might be advantageous to organize meetings so that participants can socialize and, if they choose to do so, form relationships.
- **Participants sit in close proximity:** Participants usually sit in a circle or around a table so that everyone can comfortably see and hear each other.
- **The moderator is knowledgeable in the subject area and skillful in handling group dynamics:** An effective moderator knows the topic, has memorized the discussion questions, listens with empathy and genuine interest, emphasizes that every opinion is important, is neutral in his or her responses, keeps the discussion on track, and maintains a sense of humor.
- **Open-ended questions are used:** Rather than asking questions that begin with "Why?" and tend to put people on the defensive, or questions that can be answered with a "yes"

or "no," open-ended questions are used that allow people to express opinions, explore feelings, give examples, and elaborate on ideas.

- **The discussion resembles a group interview:** Through the group discussion, group members hear each other's observations, stimulate new ideas, and generate excitement about the topic.
- **The objective is to hear all opinions, not to reach consensus:** While recurring themes generally emerge from focus groups, the emphasis is not on obtaining general agreement, but on exposing all sides of an issue in an open discussion of pros and cons.

For more information about the Dowling School Friendship Program and family focus groups, please refer to the handbook *Making Friends: Using Recreation Activities to Promote Friendship Between Children With and Without Disabilities.*[5]

Customer Service Builds Better Programs: Bloomington Parks & Recreation

Maurice K. Fahnestock
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The Parks and Recreation Division of Bloomington has been dedicated to serving individuals with disabilities since the early 1970s when a parent movement helped to create its Adaptive Recreation program. In 1988, Bloomington's Adaptive Recreation program joined three surrounding city park and recreation departments and their corresponding school districts to form the Adaptive Recreation and Learning Exchange (ARLE) Cooperative. Today, the Bloomington Adaptive Recreation program, in collaboration with ARLE, offers a wide variety of year-round recreation and education opportunities, as well as supported inclusion into all of the parks and recreation programs offered to the general public. Last year, in Bloomington alone, almost two hundred individual participants with disabilities took part in recreation programs.

In 1991, the Adaptive Recreation program was recognized in a study in the University of Minnesota as being one of the sites that used "best practices" in integrated recreation in Minnesota.[1] This case study explores some of the unique aspects of the Bloomington program that truly make it a "best practice" site.

■ Planning for Successful Inclusion and a Broad Range of Programs

To better understand the philosophy and practices used by Bloomington, it is helpful to refer to the diagram and description of the delivery of inclusionary programs, presented in *Getting Action by Taking Action: Parent Advocacy* on page 20 of this publication. In this process, there are seven essential phases that occur in the programming cycle: A) planning and budgeting, B) marketing, C) registration of participants with disabilities, D) assessment to determine individual needs, E) building of individual supports, F) monitoring and communication, and G) evaluation.

In the first phase of the service delivery model – annual planning – the staff at Bloomington work closely with the cooperative staff and the ARLE Advisory Board. The ARLE Advisory Board is made up of parents of children with disabilities, adults with disabilities, professionals in the field of disability services, school personnel, and ARLE program staff. This advisory board is divided into subcommittees which focus

their efforts in four areas: marketing, education, programming, and special events.

The programming subcommittee is responsible for reviewing the overall comprehensiveness of programming, for collecting and reviewing programming suggestions from participants and parents, and for making programming recommendations to the ARLE board and agencies to create new programs. This subcommittee allows consumers and their parents to have direct input into the offerings of the ARLE cooperative. Another subcommittee, the marketing committee, is responsible for generating new and creative ways to market its programs. One of the recommendations made by the marketing committee this past year was to try new strategies to reach school personnel and to assist them in communicating community recreation and learning options effectively to parents during special education conferences. In the past, Bloomington staff had attempted to send flyers and brochures home with special education students through the school, but no tracking system existed to determine how or if the flyers were actually reaching parents. Now, the marketing committee and program staff have created a three ring notebook labeled *ARLE Adaptive Recreation/Learning Exchange: Activities for Students.* Each Child Study Team (CST) leader in every school building will have a copy of the notebook available to him or her. An additional copy will be available to all the other special and regular education teachers in the resource rooms. Bloomington staff will make a presentation at an all-district CST leader meeting to introduce the concept of inclusion, distribute notebooks, and explain how they can assist parents to access ARLE and Bloomington programs.

Each notebook contains a variety of information, including an introductory brochure that describes Adaptive Recreation and how to access programs. The notebook also includes:

- Introductory program brochures;
- Introductory letters explaining the purpose of ARLE, the purpose of the binder, and the contents of the notebook;
- Guidelines for selecting a recreation program;
- ARLE guidelines for inclusion;
- ARLE brochure;
- Breakdown listing of individual city brochures and program offerings.

The purpose of the notebook is to consolidate the relay of information to school personnel and parents of school-aged children, and to create another way to track marketing efforts. In order to continue to expand services, a variety of other marketing techniques are utilized. The following is a brief description of some of the techniques that go beyond the generic statement in the Park and Recreation program brochure that says everyone is welcome to participate in program offerings.

■ Marketing and Outreach Efforts to People with Disabilities

Bloomington Parks and Recreation employs several methods for advertising their programs and reaching out to families that include children with disabilities. These marketing and outreach efforts include:

- Word of mouth
- Quarterly brochures
- Articles and/or press releases in local newspapers
- Generic brochures

- ARLE information notebooks to CST lead teachers
- Special education advisory boards
- Group home presentations
- Leisure Discovery Day
- Rally Days
- Presentations to disability organizations

Leisure Discovery Day is one of Bloomington's unique marketing techniques. It is a one-day event, open to students with disabilities who attend local high schools and technical colleges. The goals of the event are to:

- Give students opportunities to choose and participate in three leisure/recreation activities at no cost;
- Give community leisure professionals opportunities to introduce themselves to future constituents; *and*
- Provide participants with information packets that include resources and contact names of professionals when selecting activities that interest them.

During Rally Days, a representative from Parks and Recreation makes presentations at local semi-independent living apartment complexes and group homes. The representative describes available activities and programs and helps individuals choose activities and fill out registration forms. The representative also assists people with registering for TRAIL (Transportation Resource to Aide Independent Living) transportation. A group of parents and individuals with disabilities in the ARLE Cooperative rallied together to create this non-profit transportation service for individuals who live alone and do not have transportation services from a human service provider such as a group home. TRAIL holds annual fund-raisers and contracts with a local transportation service to provide the rides. These transportation services are available for a small fee to qualified ARLE program participants. Most of the participants would not be able to attend ARLE programs without TRAIL transportation because the Bloomington community public transportation service has a limited route and schedule.

■ Communicating for Success in Registration, Assessment, Support Building, and Monitoring

One of the most essential "best practices" that Bloomington Adaptive Recreation staff members do is to keep lines of communication open between everyone involved in the inclusion process. This means that, as soon as parents register their children for programs, the communication process begins. For some programs, the registrants simply check off whether or not they have a disability and if they wish to have a staff person contact them to assist in the inclusion efforts. The communication and assessment process then lies in the hands of the Adaptive Recreation staff who is responsible for initiating contact with the parents. In other programs, a written assessment form is sent with the registration form and the staff follow up with a parent interview once the forms are received.

Bloomington staff receive careful training in how to interview parents and participants during the assessment phase. During the interview, staff first explain to parents and participants the goals and objectives of the program, the typical staffing levels (additional staff are added only if necessary), the staff's background and training, the routine and schedule of the program, and the activities planned for the program. This background information allows

parents and participants to participate in making decisions about the kind of assistance the participant might need, how long assistance would be required, and the type of program and curriculum adaptations that may be needed. With the parents' permission, special education teachers, adaptive physical education teachers, and other program leaders that have worked with the participant are contacted as potential sources of valuable information to assist in the assessment and support building process. The parents and, if appropriate, the participants are kept informed of all the support building activities and, if necessary, a meeting is set up between the assisting aide and the participant and parents before the program begins.

Once the program begins, as in any customer service setting, communication is the key to successfully monitoring the inclusion process. The participant, parents, on-site staff, and supervisory staff members all need to have a clear understanding of the day-to-day operations and how things are going. Two of the interview questions ask parents about their preferred method and frequency of receiving information on how things are going. The staff-to-parent communication can take different forms: a brief discussion at child pick-up time, a daily or periodic phone call, or a journal entry to pass along important information. To assist participants who do not read or speak, Bloomington staff use picture agendas for each day of the program. In programs such as day camp, the camper is given a sheet of paper with pictures of each activity (such as hiking, crafts, and swimming) to represent the day's agenda. At the end of each day, staff make certain the camper takes the agenda home to be shared with his or her family. Parents have praised staff for this form of communication, indicating how wonderful it is to be able to speak with their child about what occurred at the program that day. At the end of the program, everyone's experiences – staff, participants, and parents – are evaluated.

■ Evaluation: *Did Everyone Succeed? How Can We Improve?*

Participants with and without disabilities, parents, and staff fill out program evaluations which ask such questions as "What worked well?" and "What could be done to improve the program?" The answers are collected and compiled for use in quarterly and annual program reports, as well as to be reviewed for the following year's program preparations. This allows for an open process of evaluation that continually seeks to refine and improve each program. Open communication between all parties involved builds trust and the ability to call on one another to solve problems before they start. It is also one of the best methods of marketing.

■ Two Success Stories

Michael Young has been involved with the Bloomington Parks and Recreation Division since 1990 when he was integrated into the preschool-age Discovery program. Today he is a seven-year-old boy who is sweet, shy, and has a developmental disability. Through the years, the Bloomington staff have continually nourished the relationship with Michael and his mother and have built a high level of trust. Recently, when Michael's mother called to discuss Michael's participation in the Killebrew Baseball League, staff were able to weigh the positives and the negatives with her. The Adaptive Recreation staff met with Michael and his parents before he got involved in the baseball program to help him identify his strengths and weaknesses and prepare for a successful outcome.

Michael's mother was afraid that he wouldn't fit in, that he would get teased, or that his skills would not be strong enough. After talking over her fears with the Adaptive Recreation supervisor, she felt more comfortable. Together, the program staff and Michael's mother decided to try the program with the support of an inclusion aide. Staff spoke with his team's coaches and had the aide meet with the family in advance of the program. During the games,

Michael fit in well as a Killebrew player and team member. His favorite activity was hitting the ball, his least favorite was losing. (A typical response from a nine-year-old boy!) By working together, the season ended successfully.

Michael's mom was happy that the staff encouraged him to join the baseball league. She stated, "Michael loves sports and this made him feel part of the team." She also believed that the aide provided Michael with the freedom he required to feel independent when he wanted it and enough assistance when he needed it. As his mother summed it up, "This was a good first-time experience for him." The Bloomington staff attributed the success to Michael's desire to play baseball, his mother's courage to take a risk and try it, and the trust and communication built between the professionals and family.

After Scott Jackels participated successfully in summer playground and day camp programs, a photo of three smiling children and the following note was sent to a Bloomington staff member:

> *I thought you'd enjoy this picture. Scott, Dana, and Jesse met at Camp Kota. Scott sees Jesse often, they eat lunch together at Oak Grove Intermediate School, and are taking an after-school class together. Thanks for your part in making this possible.*
>
> *— Curt & Julie Jackels*

One of the primary goals of the day camp program was to introduce the children to each other and provide a welcoming and supportive environment where children can become friends. Scott has muscular dystrophy and uses a wheelchair for mobility. At camp, he participated in all of the activities including hikes, nature study, swimming, and the over-night camp out. From the children's smiles and their mother's note, it was apparent that the program reached its goal of helping the participants build relationships.

■ Youth-at-Risk Outreach Program

Another unique program, created in the City of Bloomington in the spring of 1991, is a youth-at-risk outreach program. The program offers personal assistance to fifth through ninth grade youth and their parents in identifying and accessing summer recreation programs. Every spring, the outreach program staff work in coordination with Bloomington School District personnel to identify youth who are in trouble at school, at home, or in the community. Program flyers are mailed to each family. The program offers three levels of assistance to the youth and their families: A) information and referral, B) assessment meeting and program placement, and C) program support and ongoing monitoring.

In the first level, each identified youth and his or her parents receives a flyer on the outreach support program, along with a listing of all the summer opportunities available in the city. Then, after the mailing is sent out, each family is contacted by telephone to see if additional information is needed. Parents and youth decide if additional assistance is necessary.

At the second and third levels, an assessment and program placement meeting takes place during which an outreach staff member discusses with the youth their interests in programs and presents detailed information on potential programs. If the youths or parents feel that further assistance would be helpful, the necessary supports are put in place. These supports could include introducing the program staff to the participant before the program begins, recruiting a peer to support the participant in the program, and direct assistance from the outreach staff member during the program. Program support could also include the provision of a one-to-one aide, ongoing monitoring of the child's progress, and a high level of communication between program staff and parents. At the end of the program, each family is contacted by telephone to conduct a final interview and evaluation of the program.

In its first year, 308 youth were identified and 91 (or 30%) attended recreation programs that summer. In 1993, 457 youth were served in programs. The program has evolved over the years and now offers an after-school program and a summer outreach program.

■ Suggestions for Parents

The city of Bloomington has carefully used a customer service approach to enhance their services to all of its citizens. This has been an evolutionary process that has engaged all of the main players (parents, participants, and staff) in making it work. Out of this experience have come the following suggestions to assist parents in working with recreation personnel:

- Know what types of programs and program outcomes you want for your child and be specific about requesting them. If you are looking for learning opportunities or skill building programming, competitive sports, social-friendship building programming, or just plain fun, let staff know of these desires. If you are searching for relationship building or leisure skills programming, ask staff for particulars about how they provide participants with social and learning opportunities.
- Interview staff about the program. Ask them about the following areas:
  - Program goals.
  - Anticipated outcomes for the participants, parents, and staff.
  - Staffing – including staff-to-participant ratios; their training, background, and experience with the program and with participants with disabilities.
  - Physical setting and accessibility for the program.
  - Specific activities for participants, including each day's agenda.
  - The agency's experiences serving participants with disabilities.
- Be certain to ask staff whether the program is an established one or one they are trying to launch for the very first time. Ask your neighbors and friends about which programs have been successful for their children. As you share your goals with staff, be honest about your fears and concerns about inclusion so that staff can attempt to avoid them.
- Offer staff the names of other professionals (certified therapeutic recreation specialist, special education teacher, adapted physical educator) who know your child and who would be willing to share their experiences and make suggestions as to how to make things go successfully.
- Get to know the recreation professionals. Build a trusting relationship with them so that both you and the staff feel comfortable calling one another to answer questions, solve problems, and, most important of all, plan for success. Give them honest, immediate feedback throughout the program and request daily or regular brief reports as to how things are going. To facilitate communication, give your child a communication notebook, talk briefly with staff when you pick up your child, or make a telephone call to check in. Offer thoughtful constructive criticism and suggestions with all of the participants in mind. Demonstrate concern for all the participants and not just your own child.
- Finally, fill out the evaluation form with honest opinions and thoughtful suggestions. If the agency does not evaluate their programs, call, or write a letter to the supervisor that is responsible for the recreation programs that you have accessed.

These strategies can go a long way in building programs and services that make inclusion a reality for everyone.

After School... What Do You Do? Minneapolis Y-MAP

Jonathan A. Baik
Karen Erickson Brandt
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The purpose of this article is to share information about the range of families' and children's needs and how such needs can be addressed through community recreation participation. The focus here is on community recreation inclusion for children and youth, from early childhood age to young adulthood, who have developmental disabilities. Community options are for everyone – regardless of whether youngsters have sensory, mobility, or cognitive disabilities; conditions such as juvenile diabetes; or disabilities that are secondary to accident or illness.

By reading this, families will learn about a range of family and child needs that may be met by community recreation resources. They will learn about a variety of programs that are being developed and offered to meet these needs, including an example of a program for middle school youth called the Youth in Minneapolis After-School Program (Y-MAP), and families will be reassured about the roles they can play – indeed *must* play – to find and develop options to meet their own family and child needs.

■ Family and Child Needs

The diverse family structures and issues that exist in today's society, and the turbulent and rapid nature of social change, suggest that making generalizations about family and child needs has limited usefulness. Families must be thoughtful about identifying and defining their own issues and needs, in addition to being assertive about seeking out, arranging for, and requesting the options that will meet their needs.

The major social changes that have affected families with children with disabilities include: A) the development of successful living arrangements so that people with disabilities can reside in family homes and other community residences instead of institutions, B) advanced technologies that have improved infant survival and improved functional capacities, and C) workplace involvement of both single parent and two parent families. Environmental issues such as crime, drug and alcohol use, physical and sexual abuse, and the general safety of neighborhoods have also affected family perceptions and concerns. With this in mind, readers are encouraged to consider the following family and child needs that have been identified.

Child Development Needs

Children grow, develop, and learn all the time. It is not just during the thirteen years that they are involved in traditional K–12 school programs that their physical, intellectual, emotional, social, creative, and citizenship capacities are forming.

The period after school provides an important opportunity to nurture a child's growth. Experiential activities that are age-appropriate, diverse, stimulating, and respond to individual needs and goals can help provide a comprehensive approach to developing a child's potential. Neither organized baby-sitting nor more school are indicated. Rather, a life skills program relevant to community living can address the development of the whole child. Physical development and skills can be nurtured through physical activities. Social skills, communication skills, and learning to develop relationships can be fostered through group activities. Citizenship can be facilitated through participation in organized neighborhood service activities and in programs that integrate children and youth across cultures, genders, and generations. Emotional experience and growth can result from excitement about involvement in activities, responses to music and stories, and opportunities to learn relaxation, reflection, and communication skills. Critical thinking and problem solving skills can be developed through evaluating and selecting options and through cooperative challenge activities.

At every point from early life to young adulthood, developmental needs can be given support and opportunity for growth through community recreation options. A quality approach depends on careful planning based on assessment of the needs and interests of the participants, creative curriculum development, and thoughtful staff selection, training, and ongoing development.[1]

Latchkey Kid Needs

"Latchkey kids" are those children who need to let themselves into their homes with their own "latchkeys" and who stay in the home without adult supervision. "Home-alone" risk factors make this a problem: children may feel neglected, isolated, abandoned, unloved. They may act inappropriately or in unsafe ways. They may be treated badly by people who come into the home or who are in the neighborhood. They may not be able to cope with unsafe or frightening situations such as fires or accidents. Having little to do or subsisting on a diet of television may impoverish their development.[2]

These concerns need to be assessed by parents when making decisions about care arrangements for their children – particularly for children with disabilities. Careful assessment of safety issues together with the child's abilities and limitations is important. Problems might include gross motor disabilities that limit emergency evacuation; sensory impairments that limit awareness of emergencies and ability to call for help; and cognitive, age, and social maturity characteristics that might limit appropriate judgment about neighborhood risk factors.

Indicators that a youth might be able to be home alone include a cooperative attitude with parents and an ability to follow directions, share feelings, and demonstrate responsible independence. With these characteristics as a starting point, parents and schools need to teach the potential "latchkey kid" an extensive set of competencies that include protecting the house key, getting home from school, using the telephone, preparing snacks, managing time, getting along with siblings, dealing with fear and loneliness, awareness of neighborhood safety factors, and learning and using community resources for assistance. Guidelines for teaching such skills are available.[3] Experiential learning methods that include role-playing and practice are considered essential for children and youth to acquire these skills to the maximum extent possible. Despite these resources, home-alone self-care should typically be a parent's choice of last resort.

Parent Respite Needs

The intent of respite is to provide parents with opportunities for self-renewal through rest, recreation, or opportunities to attend to tasks and interests other than employment. Individual family needs for relief from child care responsibilities may be met by informal social supports from family and friends, by the employment of personal care attendants, and by organized child care program and activity options. These approaches may also be combined. Organized recreation and day care activities are important – and perhaps cost effective – methods of meeting parent respite needs.

Day Care Needs

This issue chiefly addresses the family and parent needs for regular, daily, positive child care arrangements that permit parents to work or attend to their own schooling and development. These needs are central to family strength and resiliency. Both preschool and school-age child care have become important needs to working parents. During the last decade, the widespread need for day care has come to be recognized as an important policy issue for the community – not just an individual family or individual child problem. The capacity of communities to finance and develop the work force, to support and strengthen family capacity and resiliency, and to safeguard and develop children and youth for citizenship has gained increasing recognition as a complex social problem of the community as a whole.

Summary of Needs

All families have a range of needs for options that will improve their children's growth toward full citizenship, and that will also help meet the needs of the parents and the family unit. Because these needs span all the formative years from birth through young adulthood, each family also needs a wide variety of options as their needs change over the years. These needs are widely shared throughout the community: that is, they require broad community response, not just individual family problem solving.

■ Community Responses to Family and Child Needs

There are many kinds of community options that could potentially respond to a family's many and changing needs. Parents may participate with their infants and young children in programs such as the Early Childhood Family Education Programs offered by local school districts in Minnesota. Organized day care may be sought for preschoolers. School-age child care that is sponsored by either public or private providers (including public schools and city parks and recreation departments) is another option. This type of service typically offers child care before and after the school day, on school-out days, and during vacation periods. Another choice is participation in activity programs that have goals of socialization, recreation, sports, skill development, community service, and similar outcomes. These services are provided by scouts, boys and girls clubs, YMCAs and YWCAs, other private non-profit community centers, park and recreation community centers, school-based after-school drop-in centers, libraries, and so on. Another piece is special interest activities such as horseback riding, sailing, wilderness adventure trips, or community theater that are usually provided by organizations that have those interests as their main service lines. Another option might be a program that is specifically geared to guide older youth in transitioning to adult interests and that focuses on a specific occupational area and provides special industry mentoring, such as a Boy Scouts of America Explorer unit.

This array of options can give families encouragement that their needs and those of their

children at any developmental point can, and probably are, being responded to by the community. If inquiry and networking do not lead to a good program, there will most likely be other families and organizations that have similar needs and interests, and will collaborate in developing a satisfactory option.

A few useful readings have been developed recently that provide guidance for responding to family and overall community needs. Examples of successful initiatives, including initiatives that focus on the needs of children with disabilities and their families, may be found in the references at the end of this publication.[4-6]

A variety of federal block grants have provided funding options to states to initiate child care and child and youth development options in community settings during non-school times. In addition, states, counties, and cities may provide local funding to meet the needs of children and families. Also, private philanthropy such as United Way, and support provided by employers, can be instrumental in starting and sustaining programs.

In general, partnership approaches among public and private agencies and consumers have been found to be effective in developing the options that people need in their communities. When these partnerships include expertise and direction from parents, together with representatives from organizations such as the Arc or United Cerebral Palsy, university consultants, and school and community practitioners, the needs of children with disabilities and their families can be responded to with relevant community options.

■ An Example of Partnership Building: *Youth in Minneapolis' After-School Program*

Background

In 1992, Minneapolis was confronted with a city-wide problem when the school release time for the public middle school students was moved up to 1:45 P.M. to accommodate school busing schedules. There had already been a long-standing need for youth development programs during the weekday afternoon hours. This target population included approximately 10,500 youth city-wide, grades six through eight, who attended public and non-public schools. There were typically few school-age child care arrangements for youth beyond the sixth grade. Youth were often home alone or unsupervised in the community; many expressed boredom and loneliness and said they primarily used television to fill their time. Without supervision, some explored their sexual curiosity or engaged in negative behaviors such as vandalism.

Donald Fraser, the former mayor of Minneapolis, initiated the Youth in Minneapolis After-School Program (Y-MAP) in response to these needs. The Minneapolis Park and Recreation Board became the managing umbrella agency. Conceived as a collaborative partnership approach among youth-serving agencies, Y-MAP attracted over one hundred agencies as partners. The goal was to have positive, supervised activity programs in every neighborhood of the city directly after school, with a wide variety of options to interest and engage youth and to meet their developmental needs. Among the agencies that were involved were parks and their community centers, schools, libraries, churches, Boys and Girls Clubs, YMCA/YWCAs, and neighborhood service agencies. Community Education directly coordinated Y-MAP programs within all six middle schools, as well as within several K–8 schools. Approximately ninety sites were operated city-wide by the collaborating agencies.

In the fall of 1992, Y-MAP began by redesigning a number of the agencies' programs to meet the priority need for activities on weekdays immediately after school. Despite the initial lack of funding, the agencies reallocated internal resources to get the activities going, demon-

strating commitment and enthusiasm as partners. This collaborative effort resulted in serving from 10% to 15% of the total population of 10,500 youth. By December of 1992, Minneapolis allocated $1,000,000 to Y-MAP for after-school programs for the 1993 calendar year.

In 1994, even though the city's allocation had dropped to $870,000 due to mandated budget cuts, Y-MAP served approximately 4,000 youth. This increase was attributed to an expansion of program offerings and the placement of outreach workers in specific geographic areas, called Y-MAP hubs, to serve as liaisons between youth, schools, parents, and program providers. Y-MAP offered opportunities in academic skills, community involvement, creative expression, intramural sports, and life skills.

Program providers, staff, parents, and youth met regularly to share programming and outreach ideas, discuss how to use funding, develop staff roles, and negotiate roles and relationships of the collaborating agencies. Y-MAP full-time staff included a city-wide coordinator, a clerk, and twelve outreach workers. Part-time positions included six school-based activity organizers, eleven hub coordinators who were located at park community centers, and numerous activity leaders.

Y-MAP distinguished itself from all previous youth-serving programs in the city because it was a collaborative partnership of a number of agencies and was a city-wide effort. Earlier programs had been limited to one or two agencies and had been narrower in scope. Y-MAP demonstrated a step forward in community development and management by linking youth-serving agencies through sharing program staff, ideas, funding, and coordinating activities.

Approaches to Serving Youth with Disabilities in Y-MAP

To manage the inclusion of middle school youth with disabilities in Y-MAP activities, Minneapolis Public Schools appointed an after-school coordinator who was also a developmental adapted physical education teacher. The coordinator facilitated the inclusion of youth with disabilities into regular Y-MAP programs; no segregated programs had been established previously. The long-range transition goal for these youth and their parents was for them to feel comfortable enough with inclusion to access regular community recreation options. Short-range goals were to develop social and recreation leisure skills. Additional goals were for recreation site staff and youth without disabilities to feel comfortable with and include youth with disabilities in activities.

The criteria for Y-MAP site selection included the provision of age-appropriate activities, non-competitive approaches, and activities that accommodated a variety of skill levels. The selected programs also needed to be offered at least two days a week and operate from 2:00 to 4:00 P.M. The regular and extra support Y-MAP options were marketed through the outreach workers, the school staff, and the after-school coordinator. In addition, University of Minnesota students in therapeutic recreation interviewed youth with disabilities in three middle schools to "talk up" the program and to assess their interests. The youth expressed wide interests in recreation, reported that they had not been previously involved in organized afternoon activities, and that they mostly watched television at home after school. They were interested in Y-MAP as a quality alternative.

Outreach workers and school staff encouraged all youth to become involved with the neighborhood programs of their choice. A constraint for all youth was that busing was provided from school to Y-MAP sites, but no transportation was provided from after-school sites to home. Youth who could arrange to get home from sites on their own, and who could participate in Y-MAP activities within available staffing ratios (about one staff person to fifteen participants) could access any program.

In order for some youth with moderate to severe disabilities to participate, however, extra staff support and busing from after-school sites to home were needed. A budget was devel-

oped to provide these services. Arrangements were made with the Minneapolis Public Schools transportation division to provide the necessary busing. Classroom educational assistants and child development technicians were recruited from schools to supplement staff and provide a staff-participant ratio of 1:4 or 1:6. These supports were used to successfully include youth with disabilities at seven after-school Y-MAP sites. Activities that youth enjoyed included video games, pool, table games, computers, gym activities, arts and crafts, cooking, video making, dancing, sports, park use, and community service.

Parents were closely involved in making the decisions that shaped the program. A key component of the service delivery process was the use of an application form that communicated information from parents to the after-school coordinator. The information on this form provided the basis for matching youth with sites, and for providing individualized information to the site staff to help them learn about the youth. Oral and written communications among the after-school coordinator, the site staff, and the parents were used for coordination, problem-solving, and program improvement.

Attendance by youth with disabilities at Y-MAP sites increased from eighteen during the initial start-up in the spring of 1993 to fifty-two a year later. In general, the youth were observed to be positively motivated and actively involved in activities. They typically commented that they had fun and made friends at Y-MAP. Socialization and friendships between youth with and without disabilities were sometimes slow to develop; structured activities such as cooking groups and video production had the most positive social inclusion and group task results.

A powerful illustration of social inclusion and activity skills development was demonstrated during one of the Y-MAP cooking programs. A large group of youth had gathered to prepare, eat, and clean up after a breakfast meal of orange juice, pancakes, and french toast. The group included youth without disabilities as well as youth with moderate to severe disabilities. Cooperative activity sometimes occurred spontaneously between the youth with and without disabilities in tasks such as serving each other and cleaning up. In other tasks, such as mixing batter, however, staff noticed that youth without disabilities assumed the task, while youth with disabilities simply observed. To promote cooperation and involvement, staff gave simple verbal prompts to the youth without disabilities to include the participants with disabilities in mixing the batter. The response was quick and positive. The youth without disabilities immediately offered cooperative assistance by holding the mixing bowl and providing hand-over-hand guidance to the others as they stirred the spoon. The response from youth with disabilities was equally prompt, including vigorous mixing of the batter. Any question about the importance of this opportunity to the youth with disabilities was answered by their facial expressions of joy as soon as they were included in the activity.

The involvement of youth with moderate to severe disabilities in the Y-MAP program was an evolving process, with many positive results. The youth enjoyed the program and had an after-school social and recreation activity. They began to develop their social and recreation activity skills. Most importantly, the comfort levels of the youth with and without disabilities, and the comfort levels of the site-based regular recreation staff, increased as they all gained experience with inclusion in community recreation. Most parents appreciated the programming schedule, with two-hour activities offered two days each week. They also were pleased with the quality of busing and support staff services that their children received.

■ Guidelines and Resources

In summary, communities are beginning to provide a wide array of options that can be used to meet family and child needs. These initiatives often have federal, state, and local govern-

ment support. Legislation has recently been developed to meet new social needs. Actual program development, however, is intended to be driven by and adapted to meet local needs. The quality of program design and delivery appears to be increasing through partnership approaches among agencies. Citizen involvement in initiating, planning, and evaluating programs is reported as an indicator of relevant and successful results. Because of these trends, families need to bring their needs and interests to the attention of the local school district – the agency that is most directly responsible not only for child development, but for community education for families and adults. Taking this initiative may lead to discovering an array of community options.

For example, inquiry about the availability of school-age child care in Minneapolis resulted in locating a program called Minneapolis Kids. This program currently serves over 1,200 children in twenty locations, and includes children with special needs. Most sites offer care eleven hours a day, twelve months a year.

Minneapolis Kids provided referral to the Child Care Resource Center, a private, nonprofit agency that is supported with state, county, and private philanthropic funds to provide information and referral to link families with child care services. They have developed a booklet to help parents choose early childhood care and education for children with special needs, with checklists of things to look for in identifying a quality environment and program. This booklet, *Child Care for Children with Special Needs: A Booklet to Help You Choose Early Childhood Care and Education,* was written by Jolee Mosher, Jodi Vannett, and Mary Ann Marchel and is available through the Greater Minnesota Day Care Association.

In addition, families should be sure to inquire about the programs available through their city and county park and recreation departments and community education departments. Lastly, social networking with other families that have children with disabilities, and using the resources of advocacy agency information and referral services, are important ways to learn and share any available new recreation options.

Family-Centered Recreation Programs: The Pallina Club & Family Rec Connections

KATHY STROM

Families can, and often do, play an integral role in developing and implementing services for their children with disabilities. While many of their roles with their children can be dictated by programs and providers, families with children with disabilities still need to function as *families*, engaging in the same leisure pursuits as those without children with disabilities. This article describes two programs that address the recreation needs of families who have children with disabilities: the Pallina Club and Family Rec Connections.

■ The Pallina Club

In the fall of 1993, the Pallina Club was launched at the Dowling School to focus on teaching bocce, an informal game of lawn bowling. Its purposes included:

- Providing opportunities to integrate children with disabilities and their families with peers without disabilities and their families;
- Teaching the game of bocce as a lifelong recreation outlet;
- Developing the social skills necessary to play the game of bocce with other individuals, both with and without disabilities; *and*
- Providing the opportunity to develop friendships, on the premise that the participants should develop peer relationships outside of the family unit.

Throughout the Pallina Club program, answers to three questions were sought: Could children with significant disabilities learn bocce? Would the program promote family participation in bocce outside of the program? Would interactions between participants occur outside of the bocce program?

Five families participated in the Pallina Club, including five children with disabilities (three girls and two boys), eight children without disabilities (five girls and three boys), and six parents (four mothers and two fathers). Only one family had two parents present.

The participants were culturally and socioeconomically diverse. Two families had African-American representation, one family had Middle Eastern heritage, and the remaining two families were Caucasian. One family represented an extended family; the grandmother lived

in the home and two cousins were a part of that home on a daily basis after school and on vacations. Two of the families were single parent families, both with the mother as the head of household; these two families relied on AFDC as their primary support. The other three families were dual income families.

The original intent of the program was to offer the Pallina Club in the evening. However, parents indicated that after school was a better time for them and that they could rearrange work schedules to attend the program. There were multiple reasons for offering the program after the school day. First, by offering the Pallina Club at this time, the children spent less time being transported between home and the school. Some of the parents believed they would attend more consistently if they did not need to transport their children both to and from the Dowling School, since preparing to transport children with special needs took a considerable amount of time. Several parents also indicated that the evening hours were typically taken up with homework and routine care such as bathing, leaving little extra time for recreation after the evening meal. Additionally, older siblings typically needed to be on the school bus by 6:30 A.M., which meant that some families had very early bedtimes.

The Pallina Club was offered once a week for five weeks. At the first session, none of the children knew how to play bocce. By the last session, all of the children had learned at least some bocce skills. All but the child with the most involved physical disability understood turn-taking and the general rules of the game. Because the families did not have access to a bocce set, none of them were able to play outside of the program. However, all of the families worked on the skills used in the game – particularly a controlled underhand throw – between sessions. By the end of the program, two families were talking about purchasing bocce sets of their own. For at least two other families, however, the cost – ranging from $20 for a small, plastic, indoor set to almost $100 for an official bocce set – was prohibitive.

Friendships appeared to develop among three of the families. By the third session, these three families were dining at a nearby fast-food restaurant and continued to do so until the end of the program. While two families had known each other from a previous school program, they claimed to have intensified their relationships during the bocce program.

During the third session of the Pallina Club, a focus group of the parents was conducted. During this discussion, parents expressed that:

- The Pallina Club, novel to all but one, was a positive experience for their families.
- They were not interested in recreation and social skill building *per se* during the program, feeling that they could teach their children these skills outside of the program.
- They were interested in ideas about how to teach a variety of recreation skills.
- While the game was new to all but one family, and was an enjoyable experience, they would have liked a broad repertoire of activities to try as a family and were interested in new ideas for recreation opportunities, especially games and craft ideas.
- They were interested in learning ways to include their children with disabilities and their children without disabilities in recreation activities that would provide positive experiences for the entire family.

■ Family Rec Connections

Based on the input from the parents at the focus group, a new program was developed for the winter of 1993 – Family Rec Connections. The program offered six weeks of activities. Each week featured a different theme and the activities presented were ones that were relatively inexpensive (typically less than a quarter per person), appropriate for elementary-aged

children, and adaptable as an adult activity, with the potential for being lifelong leisure activities. The sessions were offered once a week and each session lasted about an hour. Activities included game playing, horticulture, music, crafts, and imaginative play. The participants were the same families that participated in the Pallina Club.

When this program began in the winter, staffing included the coordinator of the project – along with three student volunteers in therapeutic recreation. The purposes of Family Rec Connections included:

- Providing a variety of recreation ideas that could be used by families to develop lifelong recreation skills;
- Assisting participants in developing skills necessary to participate in a variety of recreation settings with other individuals, both with and without identified disabilities;
- Providing opportunities for families to recreate together;
- Providing the opportunity to develop friendships;
- Providing opportunities for students from the University of Minnesota in therapeutic recreation and special education to gain experience and skills working with children with significant disabilities and their families; *and*
- Assisting Dowling School staff in developing family-centered, after-school programming as an ongoing program.

Throughout Family Rec Connections, three questions were asked:

- Can parents be taught to teach functional and age-appropriate recreation skills to their children with significant disabilities?
- Does Family Rec Connections promote family recreation participation outside the program?
- Do interactions between participants occur outside of the Family Rec Connections program?

Family Rec Connections was conducted as an after-school program for families. It was offered again during the spring of 1994 as part of the after-school programming at the Dowling School. The program offered a variety of recreation activities based on the continued input of the families, the expertise of the leadership teams, and the needs of the children.

The altered format of Family Rec Connections provided families with a variety of ideas to use at home and in the community. Each session introduced materials and ways to use them to best meet the needs of family members. An emphasis was placed on finding ways to include every family member in an activity and demonstrating techniques and materials that parents and siblings could use to teach new skills or to reinforce previously learned skills for the children with disabilities.

Student volunteers provided one-to-one interactions for the purposes of teaching skills and modeling skill development techniques for parents and siblings. They also played an important role in developing friendships between parents by assisting with the children, thus giving parents opportunities to interact with each other.

■ The Impact of Family Rec Connections

Every child with a disability received special services at the Dowling School during the school day. Three of the children had extensive medical interventions. Four of the children were on medications for various reasons and all of them experienced medication changes during the year. Three of the families had additional services provided by the county. Because of the other interventions, it is difficult to determine how much of an impact Family Rec Connec-

tions actually had on the families. However, parents and children reported many positive outcomes from the program.

The parents of the families involved in Family Rec Connections were enthusiastic about the program. While many of the ideas presented during the program were not new, parents had not considered using them with their children with disabilities. For example, one of the sessions, *Air Day,* focused on "air." As a part of that day, a variety of kites and paper airplanes were constructed. Experiments were also conducted using air and air currents. During the session, books on experiments, paper airplanes, and kites were provided. One father commented that the exposure to the printed materials was of particular interest to him.

Parents were also interested in the adaptations that were made to games and activities to allow everyone to participate. For example, on Air Day, the participants blew bubbles. A manual crank bubble gun was provided for one of the girls who had significant motor and coordination difficulties. Because the bubble solution was in the bubble gun, she had to simply turn the crank. Her mother indicated that, in the past, blowing bubbles had been more work than fun for her daughter as she tried to keep from spilling the bubble solution while dipping the blower into the solution container. The family had tried several adapted or larger bubble blowing tools and a bubble solution holder, but the gun appeared to provide greater success. The other children also perceived the child to be very successful at using the bubble gun. Due to her motor limitations, she was only able to turn the crank slowly, which is the way the gun operates most effectively; when other children tried it, they tended to crank too fast and got poorer results.

There was an observation during Family Rec Connections that the siblings of the children with disabilities played together while four of the children with disabilities appeared to seek out other children with disabilities. While the original intent was to encourage inclusion, the families, in general, were not concerned about this goal. The children with disabilities knew each other as friends because part of the school day was spent together. They had been together for some part of nearly every school day for the past two to three years. The friendships were perceived to be a natural component of the school experience.

Inclusion was occurring, however, outside of Family Rec Connections. The children without disabilities learned the activities during the program and often repeated them at home. Because they had learned skills for adapting activities, they were able to include their siblings with disabilities in activities at home. This not only increased opportunities for more quality recreation experiences at home, it also relieved some of the parents of being the primary or sole provider of recreation activities for their children with disabilities. One mother called Family Rec Connections "teacher training for kids." The activities that were implemented during Family Rec Connections were also used by the families with friends, other extended family members, and in community settings such as Sunday School.

The exposure to a variety of materials assisted families in determining what toys to purchase for the children with disabilities. During Family Rec Connections, families were able to test out a variety of materials and to learn alternative ways to use them to accommodate individual child abilities. For example, a day was spent in the gym with a variety of balls and frisbees. The families were able to try each one with the assistance of the student volunteers and the coordinator. By having several similar items available concurrently, parents were able to compare how the materials worked for their children. Because of the cost of these materials, trying them out before having to purchase them for home use was welcomed.

Families were also exposed to alternate uses for materials. For instance, none of the children with disabilities could draw well. Coloring with crayons and markers, nonetheless, was a preferred activity for all but one of the children with disabilities and all the nondisabled peers. During one session, families were able to try sturdy rulers and templates typically used

for drawing in drafting and quilting. The children without disabilities were encouraged to use quilting template plastic to make shapes for their siblings to trace. Hand-over-hand coloring techniques were demonstrated, particularly for two girls who had considerable difficulty holding a crayon or pen. Both of the girls used the techniques at home and were coloring more independently by the end of the spring session. All of the children with disabilities had coloring as a preferred activity by the program's end.

Family perceptions of barriers to recreation also changed as a result of Family Rec Connections. Initially, families perceived recreation to be costly and time consuming. Recreation for families was primarily seen as outings to such places as the zoo, parks, movies, shopping malls, and museums. By exposing them to activities that were inexpensive and could be done in a short amount of time, families were able to change some of their misconceptions about what recreation was.

Finally, the parents appreciated the opportunities to share with the other parents. It was important for them to share their concerns and frustrations about their children. Because the parents were often well informed on resources and were very willing to share their expertise, it was not unusual for parents to find solutions to problems based on the others' experiences.

■ Where is Family Rec Connections Now?

Family Rec Connections has evolved into a six-week program that is offered in conjunction with the regular after-school programming at the Dowling School. A single hour-long session is offered each week. An extra half hour is reserved so that families can finish an activity at Family Rec Connections if they choose.

While the initial program included the same families for an entire school year, the current program is open to any family who has a child with a disability attending the Dowling School. This new participant format was in response to two needs. First, families with children with disabilities are like other families in that their schedules change with the seasons. In the initial cohort, one family could not attend one trimester because their daughter had a conflict with music lessons. Another family had difficulty attending in the spring because their child played softball. Two families had a parent in school whose schedule changed each quarter. Because of these schedule conflicts, participation was sporadic. The second reason for changing the participants was to expose more families to the program. There are about fifty children with identified disabilities at the Dowling School: by welcoming all to register, more of these families could have an experience in Family Rec Connections.

A more specific format has also been established. The same basic six sessions are used for each of the trimesters. By using this format, it is easier to train others to lead the program. It also provides repetition for families that choose to participate more than once, which is an effective tool for learning. Because the sessions are somewhat structured, quiet toys are provided at every session for children who may have difficulty staying attentive to an activity. Student volunteers typically assist the children who have difficulty staying focused or who choose not to participate in the primary activity for some reason.

The first session of each trimester is an introductory session. During this session, it is important for the leaders and the families to take time to get to know each other. It is also important to determine what each family sees as their needs, what their recreation preferences are, and what the family members have in common concerning recreation. This is done through the use of games and a mapping activity. To start the session, an ice breaker game is used. For example, a favorite game is called *Hoopla*. In Hoopla, everyone stands in a circle. A hula hoop is hung over one person's arm and then everyone hold hands with the people on either side of them. The object of the game is to pass the hula hoop around the circle while

everyone continues to hold hands. Each person must find a way to go through the hula hoop. If a person uses a wheelchair, or for some other reason cannot get through the hula hoop, the group must design a solution for completing the game. The process helps the participants to strategize on ways to include everyone. By brainstorming together on solutions, they also get to know one other.

The group then moves to a quiet activity. During this time the parents tell the group what they see as barriers to family recreation and a recorder writes these barriers on a large piece of paper. Once barriers have been identified, a large piece of paper is distributed to each family. A recorder from each family makes a box of some sort for each family member. The family works together to fill in the boxes with what the individual family members like to do with their leisure time. They then draw lines between all of the similar activities to see how much common interest exists for recreation activities. The charts are then shared with the group. These activities assist with determining what the families needs may be. They also assist participants in seeing commonalties of needs across families. Finally, participants are able to find others with similar interests.

The second session is a theme day. While the topic may change for a variety of reasons (e.g., seasonal changes, participant interests, imminent holidays) the purpose is to provide families with opportunities to brainstorm about potential activities, to use activities typically used for special events or parties for family recreation, and to provide ideas on where to look for resources. *Apple Day* was the theme for the fall session. The session began by making stamps with apples and paint. Each participant was provided with paper, paint, apples, and plastic knives. Different designs could be made by cutting the apples different ways. The cut apples were dipped in paint and pressed onto the paper. A child who had quadriplegia sat next to his brother. His brother let him smell and taste the apple and feel the textures. A book on apples was then read to the children. The session ended by listing all of the foods containing apples that people could imagine. This session provided the families with a simple, cost-effective activity that could be generalized to other settings. It also encouraged use of the library to find new reading materials. Finally, the families were able to go home and prepare some of the ideas for foods with apples. Since apples were inexpensive, families were able to do apple activities for the remainder of the season.

The third session is a games session. During this session, families are introduced to items which are common to many games such as dice and cards. They are also introduced to games that are typically used in the children's classrooms. The participants and group leaders assess the skills needed for a variety of games. This assists parents in determining what skills they need to teach their children. It also assists them in learning how their children can generalize their newly acquired skills from one activity to another. Resources for learning how to participate in the activities are provided, including books and curriculum materials.

The fourth session, "Flying Things," is conducted in the gymnasium. This session allows families to test a variety of balls and frisbees, juggling scarves, and other toys that are typically thrown and to see what works best with their children. All of the materials, except the frisbee, a "foxtail", and a plastic bocce set are soft, to keep the environment relatively safe. The harder materials are used with direct supervision from parents or staff persons. The materials are readily available in local stores and typically cost less than ten dollars. Many of the items cost less than five dollars.

The fifth session focuses on where to locate activities. For this session, families are supplied with highlighters, markers, stickers, a set of free resources within the community (neighborhood newspapers and other free papers that are typically found in restaurants and entertainment sites), a community education brochure, a parks and recreation brochure, the Sunday newspaper, and a calendar. The families work together to identify activities that are

of interest to family members. They fill their calendars with ideas so that they have a menu of recreation options for the week ahead. They can use markers, stickers, or highlighters to match family members' interests with activities. An important component of the session is that the participants share openly with the group. It is not unusual for participants to share information on events that are occurring in the community that may be of interest to the entire group. They may also share information about what is occurring at the Dowling School. Ongoing attractions such as the Science Museum of Minnesota, the zoos, and art and theater attractions are often discussed.

The final session focuses on inclusion in community recreation. The participants are introduced to strategies for contacting agencies, asking for accommodations, making their expectations known, and working with agencies to facilitate inclusive services. Whenever possible, personnel from community recreation agencies are included, fostering a two-way conversation that assists both the parents and practitioners in identifying barriers to the inclusion of children with disabilities and their families in community recreation programs.

■ Outcomes

Family Rec Connections continues as an after-school program at the Dowling School. The longevity of the program suggests that families with children with disabilities have a strong desire to be with other families with children with disabilities. It is a program that families choose to return to, suggesting that repetition, among other things, is perceived by parents to be an important learning tool.

One mother summed up her perceptions of the importance of Family Rec Connections and community recreation in general, in a letter to recreation practitioners. The letter, below, could be a message to other parents and teachers as well:

> *My family's participation in Family Rec Connections offers some advantages that may otherwise be limited or beyond reach. For starters, Family Rec Connections is a source of family outing or togetherness. It allows both the disabled child and his or her family to spend time with other families who are dealing with some of the same challenges or situations.*
>
> *Having a child with severe disabilities can restrict activities outside of the home for the entire family. Even though facilities exist that are handicapped accessible, they are not necessarily staffed to accommodate the special needs of the disabled individual. This can be difficult on other siblings in the family who may otherwise lose out on a day of fun.*
>
> *Family Rec is set up to help families work together on things to do that would include everyone. It also gives parents an opportunity to see what their disabled child's limitations may be. Sometimes it's hard to decide on activities for such a child because you are unaware of what they're actually comprehending; their tolerance for a particular activity or sport; even problems with socialization.*
>
> *Including my daughter in all activities is extremely important because she is a vital part of the family. Even though extra time and care is given in making these choices, it is worth every minute. Disabled individuals should not ever be underestimated or slighted because it's near impossible to tell what or how much they may be able to achieve. But, if given the opportunity and exposure to different settings, they have a fighting chance.*

Family Rec Connections is but one solution to the many issues that face families who have a child with a disability. However, a program such as this is a place for families to start or continue to learn how to include all members of a family in recreation activity. It is a place where families can go for ideas and support from other families and recreation professionals while working to make the best possible world for their family members.

Mixing Kids & Seniors at the JCC Intergenerational Program

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The JCC Intergenerational Inclusive Preschool Program is a five-year collaborative effort between the University of Minnesota and the Jewish Community Center of the Greater St. Paul Area (JCC). The program brings children with and without developmental disabilities, ages three to five, together with senior adults to learn through creative educational play.

There are three primary purposes of the program. The first is to promote intergenerational interaction between older adults and preschoolers with and without disabilities in a preschool setting. During the five years, outcomes for and benefits to the children and the seniors will be evaluated. For example, it is expected that the senior adults will learn to provide the extra assistance children with disabilities may need in classrooms, the special acceptance, nurturing, and an example of being valuable through the life span.

A second purpose of the program is to determine the effects of older adults serving as assistant project staff on the seniors' self-esteem, self-efficacy, and decision-making skills. Of particular interest is the carry-over effect that participating in the project might have for the older adults in the home environment.

The third focus of the program looks at the children's play environments in the classroom as defined by a curriculum called the Creative Curriculum. By observing the interactions between the children as well as their play behaviors, the play environments that successfully promote appropriate play and social interaction between the preschoolers with and without disabilities can be determined. By examining play situations, the teachers can also learn to make their classrooms truly inclusive experiences for all the children, further develop their skills in implementing the Creative Curriculum, and fine tune their problem solving skills.

Through this program, it is also anticipated that preschoolers will learn to accept differences in age and ability. They will learn to respect and appreciate the differences as opportunities for them to "shine." In time, it is hoped the that children will begin to feel the intergenerational mix and the inter-ability mix are natural.

■ Program Beginnings

The idea for the project grew out of the personal and professional interests of JCC staff members and professors at the University of Minnesota. JCC staff members who were key players in conceiving

the program included the Special Needs Director, the Child Care Services Director, the Senior Adult Supervisor, and the Assistant Executive Director. The JCC had a ten-year history of including older children and youth with disabilities in regular programming. The Special Needs Director was a certified therapeutic recreation specialist with knowledge and experience in facilitating inclusive programs. Staff had noticed that there were senior adults on the opposite end of the building from the preschool who waved at the children when they saw them. And there were children with and without disabilities whose families wanted them to benefit from an excellent preschool. As such, the setting was ripe for an intergenerational, inclusive program.

The Child Care Services Director saw the potential benefits of including children with disabilities in her school. She valued the goal of having the student body reflect the natural proportions of children with and without disabilities that exist in society. She believed the children without disabilities would interact with children with disabilities and learn immeasurably important lessons for life. They might discover things about themselves that otherwise might elude them. They would develop new skills that had to do with being a person in a society where people who are different contribute to that society in varying ways. Some of the children in the preschool were of different racial and religious backgrounds. The curriculum encouraged appreciation for those differences and the classroom environment reflected that through pictures of children of different backgrounds. Through the project, the children would have daily opportunities to learn about those who were different because of disability, disease, infection, trauma, or other influences in the environment.

The Senior Adult Supervisor knew – both intuitively and through experience with older adults – that a kind of magic can happen when older persons have opportunities to be with young children. She was aware that many of the seniors had grandchildren and even great grandchildren whom they sometimes saw less frequently than they would have liked. There were other senior adults at the JCC who had no grandchildren, but wished they had. Senior adults, in general, frequently voice concern about the current state of disrespect for and ignorance about older persons by young people in the United States. They agonize over reports of acts of violence against seniors, intolerance, and devaluation of older people displaced by younger people. Some seniors express the opinion that the cause of such problems between the two ends of the age spectrum is partly due to insufficient contact with older persons in the younger years. The problem is seen as exacerbated by the societal value assigned to paid productivity through jobs and tangible products. Along with these concerns, the senior adults at the JCC looked for interesting ways to occupy their time. Many were excited to attempt new experiences and wanted to learn new skills. The Intergenerational Inclusive Preschool Program seemed to address all of these issues.

The Assistant Executive Director also shared the enthusiasm for the intergenerational program. She viewed the program as a natural continuation of the JCC's commitment to include people with disabilities into ongoing programs. She also saw the potential value to the early childhood program and to the senior adult program in terms of strengthening the existing programs, thereby better serving the respective participants. Additionally, this program could attract new families to the JCC, thereby serving the greater St. Paul area in new ways.

At the University of Minnesota there were three other key players who participated in initiating the program. One faculty member, who taught in the area of therapeutic recreation, had expertise in including persons with disabilities in recreational pursuits. Another faculty member, who also taught in the area of therapeutic recreation, designed, implemented, and evaluated recreation programs for older adults. The third university faculty person taught in the area of special education, with a focus on the education of preschoolers with disabilities. Thus, the three components of the Intergenerational Inclusive Preschool

Program were well represented for the design and evaluation of the project. Additionally, faculty members could seek funding and provide staff for the project.

The four JCC staff members met with the three university staff to design the project. JCC staff then engaged support from the Executive Director and the other JCC staff, as well as from the Board of Directors who made the final decision confirming the collaboration between the JCC and the University of Minnesota. With start-up funding, a project coordinator was hired and the pilot study began in the spring of 1994 by advertising for and attracting several senior adults, informing members of the JCC that the project was going to take place, and beginning the initial data collection process to determine how the project should actually work.

The first year was also spent gathering information about intergenerational programs that had been attempted in other settings. The review of literature revealed many important facts about the value of such programs for people of all ages. It also shed light on important strategies to keep in mind regarding different learning styles across the life span and the needs that must be addressed for seniors to feel compelled to make a long commitment to an intergenerational project.

■ Benefits of Intergenerational Programs

Intergenerational programs have been demonstrated to be beneficial to all age groups.[1] Elderly persons are an untapped resource for schools. Children get additional attention as teachers are freed to give more individualized instruction. Older adults feel valued, powerful in their ability to share knowledge and skills, and virtuous in their passing along moral standards by example and by discussions with children.[2-4] Intergenerational programs often result in more positive attitudes toward the elders. They gain or regain status in the eyes of parents, teachers, and in their own family's eyes. Likewise, the older adults find ways to relate to younger generations as they come to understand current trends. They realize that the well-being of the young must be their treasured legacy if society is to progress.[5]

Barrow[6] and Metcalf[4] have each presented solid information about the learning styles of older adults and how these learning styles change throughout advanced years. They have demonstrated that people have the capacity to learn new skills until death though the rate of the acquisition of knowledge and skills changes. Simply stated, both the very young and old learn new information better if it is offered in small segments and is frequently reinforced and practiced. Both groups attach new information to that which they already know and remember easily. Both prefer to learn about topics of their own – rather than another's – choosing. Therefore, guided discovery is the preferred approach. Since both young children and older adults share some commonalities in terms of learning styles, an intergenerational program seems quite ideal.

■ Program Description

This section explains how preschoolers with disabilities were included in the JCC early childhood program, how elders were recruited and trained to support the children in their classrooms, and how all staff members worked together to promote inclusion.

Including Preschoolers with Disabilities in Classrooms

Including preschoolers with disabilities in early childhood classrooms followed much the same process as including children with disabilities in any JCC program. When a family approached the JCC to enroll a child with a disability in the early childhood program, class-

room assignments were made by the Child Care Services Director based on the child's age and the room capacity (usually fourteen to sixteen children). Families could choose from among several schedule options when enrolling their children in classes, ranging from two mornings a week to five full days a week. (This same procedure was followed when families with children without disabilities requested enrollment in the program.) Typically, only one child with a disability was assigned per classroom along with approximately fifteen peers of the same age who did not have disabilities. This proportion was used because it reflected the approximate number of people with disabilities in society at large (the ratio typically given is one person with a disability to ten people without disabilities), the classroom teachers could meet the needs of the children without feeling overextended, and the number of additional adults who might be needed to assist children with disabilities in the classroom could be kept at a minimum.

Upon confirming enrollment (which usually occurred several weeks if not months before the child's actual involvement in the classroom), the Child Care Services Director contacted the Special Needs Director to assist in assessing the child's needs and abilities. A meeting was set up with the family in which needs, abilities, goals, and concerns related to such issues as physical handling, inappropriate behaviors, mobility, medication, and transportation, to name a few, could be discussed. Based on what was learned from this discussion and the degree of experience that classroom teachers had working with children with disabilities, as well as other classroom variables – such as children's activity levels or their ability to play independently – a decision was made regarding whether a support staff person, referred to as a "trainer advocate," would be needed to provide one-to-one assistance to the child with a disability. This decision was made collaboratively, with input from parents, classroom teachers, the Child Care Services Director, and the Special Needs Director.

Subsequently, and prior to the child entering the classroom, a meeting between one or both parents, the child with a disability, classroom teachers and aides, the older adult, and the trainer advocate (if one was required) was arranged by the Special Needs Director. At this meeting, introductions were made and everyone present was made aware of the child's and family's important needs, goals, and considerations. If one or more of these key players were unable to attend this meeting, communications were conveyed individually by the Special Needs Director.

Recruitment of Elders

Once a child with a disability was enrolled in the preschool, an older adult was recruited and matched one-to-one with the child. Recruitment was accomplished by several methods – flyers mailed specifically to older adult JCC members, recruitment talks at JCC events that older adults typically attended, agency newsletter articles, announcements on bulletin boards, as well as word-of-mouth. Rather than relying on a single recruitment strategy, this combination of recruitment tactics was necessary to reach the broad range of elders who took part in the many activities the JCC offered. In these outreach efforts, the main selling points for the older adults were the intergenerational aspect of the program and being able to help a child with a disability – that is, a child who without assistance would not be able to participate in the preschool successfully. Having had little prior experience or contact with people with disabilities, the elders were interested in children with disabilities, empathized with them, wanted to form new personal relationships with them, and wanted to make a contribution to their communities by helping them.

Older adults were matched with children with disabilities based on their schedules and the ability of the older adult to meet the needs of the child. That is, if a child had an especially high level of activity, needed to be lifted often, or required considerable physical assis-

tance, he or she was matched with an especially active and vigorous adult. If, on the other hand, the child responded well to verbal instructions and being shown how to use play materials through example, an adult who could provide this type of assistance was selected. All the older adults were willing to assist any of the children with disabilities, regardless of the level of assistance they might require.

Training of Elders

The training of the older adults was accomplished through both formal, scheduled meetings and informal, in-classroom communications. Initially, the older adults took part in individual interviews. They were asked about why it was important for them to be involved in the intergenerational program, their prior experiences working with children with disabilities, their expectations and concerns about the program, their feelings of self-efficacy, and the amount of time they could volunteer. The answers they provided served as a measure for the amount of training they later received.

Before the older adult became involved in the classroom, he or she was introduced to the family and made aware of the child's needs and abilities and how to best respond to them. Communication with the family was essential for learning about the child and reinforcing parents' goals in the classroom. The older adult also visited the classroom and spoke with the child's teachers in order to learn about the classroom environment, activities, rules, schedules, and teacher's goals and objectives. The Special Needs Director (and trainer advocate if one was needed) provided instruction in inclusion strategies such as special teaching techniques, adaptations, and cooperative groupings, as necessary.

As part of their training, older adults were also given a copy of a job description that outlined the role they would play in the classroom. This job description emphasized the importance of giving children opportunities to interact independently with play materials and other children before offering assistance. It also outlined how a child's involvement in the group could be encouraged through providing verbal reminders or additional instructions, showing children how to use play materials, and encouraging social interaction with classmates. Classroom teachers were also given job descriptions related to inclusion. Their role emphasized the importance of working as a team with older adults to support the children's inclusion in classrooms. That is, rather than expect the older adult to tend to all the needs of a child with a disability, teachers were asked to also interact with the child and address his or her needs, just as they would do for any other child in the classroom. The teacher's active involvement in promoting inclusion was essential for setting a tone of acceptance and equal participation in the classroom. Their involvement also freed the older adults to assist and form relationships with the other children in the classroom.

To give older adults a clear designation as early childhood staff, they were given the same JCC staff name badges that all the early childhood staff wore. As older adults began working in classrooms, they attended the same monthly staff meetings that all the early childhood staff attended. These meetings provided staff with opportunities to work through problems, communicate, collaborate, and receive additional training related to early childhood education or inclusive recreation. Additional training that the older adults received was provided on a one-to-one, situation-specific basis by the Special Needs Director, classroom teacher, or parent.

Involving Older Adults in Classrooms

With this advance preparation and training, the older adult was introduced to the children in the classroom as a "new teacher" rather than as a "special helper" for the child with a disability. The introduction was made in this way to reduce the potential stigmatization that

might occur to a child who was assigned a special helper when no other student had a helper, as well as to give all the children opportunities to benefit from contact and interaction with the older adult. Typically, older adults assisted children in classrooms two to three times a week for approximately two to three hours each time they came.

At the preschool, children had opportunities to participate in a number of free play or organized activities throughout the day. During free play, children could choose to play at six or seven play stations that were set up around the room. Examples of play stations included art, blocks, carpet toys, computer, dramatic play, library, sand and water, science, and table toys. The materials that were presented at the play stations changed from week to week. For example, for the dramatic play area, play materials for a pretend construction site might be available during one week; during a subsequent week, play materials for a pretend restaurant might be presented. Free play also included informal playground activities. Organized activities included group time, reading books aloud, music, gymnastics, swimming, mealtimes, and special events such as a puppet show, field trip, or theater production.

The first priority of the older adults was to provide whatever assistance the child with a disability might need to participate as fully and successfully as possible in the activity and with the other children. In addition to this responsibility – and depending on how much assistance the child required – the older adult also fulfilled a number of other tasks in the classroom. For example, the older adult distributed play materials, assisted children with operating toys, read the children stories, provided encouragement and positive feedback, and reminded children to respect each other and play well together. Along with the valuable assistance they provided the children with disabilities, teachers commented on the many ways in which older adults assisted teachers in classrooms – by giving them an extra pair of hands upon which they could depend.

Whenever problems arose, the Special Needs Director and Child Care Services Director served as on-site contacts for the older adults to provide guidance, discuss options, arrange meetings, or serve as mediators. Throughout the involvement of older adults and the inclusion of children with disabilities, ongoing communication between the older adults, parents, teachers, trainer advocates, Child Care Services Director, and Special Needs Director was essential to keep attuned to changing needs, schedules, and developments in the program.

■ Outcomes

Ida, age 85, volunteered to assist Melanie, age 4, in her classroom because she "wanted to do something that's productive." Twice a week Ida walked five blocks to the JCC, with the help of her cane, to assist Melanie. (In inclement Minnesota weather she arranged a ride through the JCC senior shuttle.) Each morning, as Ida walked into the classroom, not only Melanie but all the children would greet her with a big "Hi, Ida!"

Even though Ida said she felt "inadequate" at times when assisting Melanie, she thought it was important for her to take on the challenge. She explained, "There were a lot of times that I said, 'I don't think I can do that' but then I said, 'Yes, I *can*.' Like when I picked up Melanie the first time. I was scared. I really was scared. She just jumped into my arms on the playground – all of the sudden there she was – so I just dug my knees into the sand [and caught her]."

Ida believed participating in this program has made a difference in how capable and valuable she feels. She said, "Well, I feel a sense of accomplishment. You try to do something that's productive, and I would say this is productive."

When Sidney, 73, read the recruitment flyer that was mailed to his home, he called the JCC saying he wanted to be involved in the program for humanitarian reasons and because

he missed his grandchildren in Arizona. Sidney was matched with Zach, 5, who was the same age as his grandson. "Zach's like a surrogate grandchild for me," Sidney explained, "It's as if I'm playing with my own grandson."

In the classroom, Sidney formed a rapport with Zach, helped him play and get along with the other children and, when Zach's attention wandered, brought his focus back to the game or activity in front of him. Besides helping Zach, Sidney was also there to help Zach's classmates. Sidney assisted children in solving playground disagreements, provided an extra ear to listen to a child's lament, and helped children put on and take off their jackets. He laughed and said, "I'm known as the *zipper-upper*!"

As much as Sidney helped Zach and his classmates, Sidney thought they did more for him than he did for them. Sidney appreciated how the experience gave him something worthwhile to do after retirement. He observed, "I think there's a tendency for people like me to have a tough time getting used to retirement. I've only been retired for two years so it's still hard. I miss the social part of my work and this is a nice substitute." Sidney continued, "I really feel I've done something to help. I feel that I am doing something useful. I get a kick out of [Zach's] reactions to me. Just seeing these kids – they keep me young! I get a lot of satisfaction out of it."

When classroom teachers were asked what they thought about elders joining their early childhood staff, they responded overwhelmingly with praise. Having an older adult in the classroom, they said, gave them extra time to provide individual assistance to children or to organize an activity. Staff commented on the many ways senior adults helped out in classrooms, how the children "loved" them, and how the preschoolers would run up to them the minute they came into the room. The staff's response was so favorable toward the senior adults that teachers who did not have children with disabilities in their classrooms began to inquire, "Why can't I have a senior in my classroom, too?"

Parents also felt their children with disabilities benefited tremendously from the extra assistance the elders provided and from the intergenerational exposure. For instance, Melanie's mother, like many parents at one time or another, occasionally had difficulty coaxing Melanie to go to school. Her most persuasive strategy was to tell Melanie, "You'll get to see Ida today!" and she was ready to go.

Another parent spoke eloquently about the value of the intergenerational component of the program, "I really like that 'grandparent' aspect. They have just everything to contribute – the mentorship, they have so much life experience – and their wealth of knowledge and patience after having been through so much over the years. Kids don't have too much experience with elders. I think it's a vital connection that has really been lost in society today. I think it's real important to develop that relationship. I just think the extended network is very important."

■ Guidelines for Parents and Practitioners

Several practical guidelines that parents and practitioners might find useful have been developed through the Intergenerational Inclusive Preschool Program. Regarding ideas for families, if a child's preschool does not currently involve older adults, a parent might suggest to the director that this valuable resource be tapped. Older adults can be recruited through advertisements to the general community or to a senior citizens center and brought into the classroom. Children can also form ongoing relationships with residents who live at nearby health care facilities or apartment complexes.

If older adults are already assisting in an early childhood program, families are encouraged to communicate openly and directly with the older adult about the child's needs and

growth, just as they typically would talk with the classroom teacher. In most cases, older adults will appreciate any insight or information a parent might offer – not to mention reinforcement for the contribution they are making to the child's nurturance and well-being. Families can also extend invitations to the elders to join them for important events in the families' lives, such as birthday or holiday celebrations. Many older adults volunteer to expand their social contacts and become more involved in their communities. Shared family time apart from the preschool setting can strengthen the bonds between the youngsters and the elders, and reap benefits for all the generations in between.

For staff who work in intergenerational preschool programs, or who are considering designing such a program, there are several issues to consider. For example, when recruiting older adults, it is helpful to use a variety of methods. As noted earlier, volunteers can be recruited by mailing flyers to potential recruits who are on a senior adult mailing list, by giving recruitment talks to events that older adults attend, through newsletter articles, through postings on bulletin boards, as well as by word-of-mouth from current volunteers.

Because many older adults live active, busy lives, it is important that staff be flexible in the expectations they place on older adults' time and schedules. It is also important to keep roles "fluid" between older adults, classroom teachers, and trainer advocates when working in inclusive classrooms. All staff members – not just older adults or trainer advocates – should be encouraged to step in when children with disabilities need help. Classroom teachers may need to be reminded of the key role they can play in setting the stage and tone for inclusion. As a rule of thumb, in most cases, teachers would want to give just as much attention to the child with a disability as to the children without disabilities – and probably no more.

To facilitate classroom inclusion, roles may need to be clarified for the older adults, trainer advocates, and teachers. Job descriptions may need to be developed that clearly specify each person's responsibilities. These job descriptions should be tailored to meet individual needs. That is, some people may only need a few verbal directions in order to understand what is required in different situations; others may need activities and roles to be identified in writing. A staff person may need to strike a balance between giving older adults very specific information and training regarding a child's needs, and allowing the person's natural and unique "grandparenting" skills to emerge. In general, one should avoid over-scripting or over-directing the older adult (unless, of course, the person finds this useful).

Staff can increase the comfort level of elders in classrooms by teaching them the games and activities of the curriculum before they actually begin working with the children. In doing so, older adults will feel more competent in their broadened leisure repertoires and prepared to do an effective job. It is also essential to share classroom procedures and rules with seniors so they are aware of whatever protocol is important to follow or whatever boundaries are important to respect. When identifying classroom tasks for older adults, staff should keep in mind that some elders might not be comfortable performing certain tasks – such as changing diapers, lifting children or heavy objects, pushing a wheelchair, or other physically demanding tasks. If this is the case, classroom teachers, aides, or trainer advocates may need to share in these responsibilities. Frequent opportunities for older adults to practice safe handling or lifting procedures would be important to arrange. As older adults assist children, they may need to be cautioned about providing "too much" help, thus creating a dynamic of dependency between the elder and the child. Children should be given ample opportunities to attempt activities on their own before assistance is offered. Additionally, if an older adult appears discouraged that a child's progress is slow, staff may need to remind him or her that growth for the child may be realized in small segments and that changes may not be very obvious except when viewed over time.

Lastly, and most importantly, staff can play a critical role by frequently reminding elders

- of the value of their efforts and contributions. Staff's appreciation can be shown through a casual comment in a school hallway, a special acknowledgment at a staff recognition party, a newsletter article, a note of gratitude, or in a birthday card. Elders' unique contributions can also be recognized by inviting them to share information about their lives or lore about how things were done when they were a child or during other periods of their lives. For example, elders can teach children the art of making latkes, share a game that was popular when they were a child, provide instruction in their favorite hobbies, or tell children stories about their families. Regular affirmation of the valuable roles that older adults play in the lives of all of the children in the intergenerational program will be greatly appreciated.

PART FOUR

A Vision for the Future

Inclusion in Community Leisure Services

STUART J. SCHLEIEN

Participation in inclusive leisure programs can make life-changing differences for children and youth with disabilities. It is not only people with disabilities, but also the community as a whole, who benefit from these programs.

For instance, the community benefits as recreation professionals continue to grow more accepting of individuals with disabilities and accommodating of all people. On attitude assessments, recreation personnel have indicated that inclusive services have taught them not to be afraid of people that are differently-abled, and that individuals with disabilities are disabled only to the extent that they are perceived to be. Indeed, recreation personnel are learning that, with careful attention to design, inclusion works to *everyone's* benefit.

In the early days of inclusive community leisure services, it was commonly believed that by simply changing the physical environment of an agency to remove its architectural barriers, bringing people with and without disabilities together in that setting, participants would interact positively and have successful social and leisure experiences. Sometimes these strategies alone did have that fortunate effect. But, as we have learned – sometimes the hard way – physical accommodation and physical proximity alone do not usually produce positive interactions and attractions. In fact, a backlash often occurs when individuals who significantly challenge the service delivery system have been "dumped" into programs with minimal preparation. The "seeds" to produce positive attitudes and accommodating ways do not automatically get planted: they must be sown and then cultivated in carefully structured (programmatic) ways before "harvests come in." The ultimate challenge is to create fertile and healthy environments within which all citizens receive continuous opportunities for growth and nurturance.

Who will be responsible for these changes in attitude and willingness to accommodate? When and how will community recreation agencies accommodate all children and youth? And, if these efforts do become successful, will they endure over time? One thing is certain: as individuals with disabilities become increasingly involved in inclusive community recreation activities, new methods to increase communication between participants, family members, and practitioners will become necessary. Alternative and creative avenues for meaningful collaboration and dialogue need to be explored.

One factor that works in favor of the inclusive community recreation movement is that family members are

becoming increasingly involved in and more vocal about decisions concerning the quality of their children's lives, whether they live in or out of the family home. In fact, the U.S. Senate recently agreed to re-authorize the Elementary and Secondary Education Act. Section 315 of this act contains the Families of Children with Disabilities Support Act of 1994. This family advocacy legislation includes services and support for families in their efforts to promote the inclusion of their children with disabilities into all aspects of community life. It also promotes the use of existing social networks, natural sources of support, and building connections with existing community resources and services. However, interest in working closely with families should not occur simply because it is the appropriate thing to do or because the law requires it. The time appears ripe for significantly more collaboration among key players.

Attention to the trends for increased family support and for community involvement will be of great importance to the viability and quality of inclusive community leisure services in the future. To facilitate active involvement of consumers and family members, recreation practitioners must step out of their agencies' doors and into the community to communicate clearly a willingness and readiness to accommodate those previously unserved and underserved individuals. Sustainable systems change in inclusive recreation services will only become a reality when parents and practitioners communicate often with each other.

So what next? In increasing numbers, parents need to begin to help recreation agency staff identify preferences for activities and then support agency efforts to generate appropriate adaptations to enhance their children's participation in programs. Also, parents can serve on advisory boards to assure that inclusive services are promoted and supported, agency staff receive training, and sufficient volunteers are recruited. One collaborative strategy described earlier in this publication, the *focus group* strategy, is a means of bringing key stakeholders together to discuss all sides of an issue and to stimulate development of meaningful recommendations and solutions. Through this focus group approach, recreation practitioners can stay in touch with the needs of children with disabilities, family members receive opportunities to voice their opinions, and key players work together to increase each other's understanding of their respective needs, preferences, constraints, and solutions. In this manner, whole communities can mobilize around this social inclusion goal and combine resources for problem-solving and program development.

In closing, we propose that the following four ideas become essential ingredients in guiding the development of inclusive leisure services:

- Programs must be designed for people that are *age suitable* and are based on personal *interest,* not on a diagnosis or label.
- Programs that *prepare* people for inclusive recreation participation must occur in their *home communities,* not in restrictive, contrived, and remote settings.
- *Communication and coordination* between participants, family members, and practitioners must occur if inclusive services are to be initiated and thrive over time.
- Participants with and without disabilities, family members, and leisure service providers must assume a *shared responsibility* approach to help ensure that every community member's needs and interests are met, including the recreation and social needs of entire *families.*

No longer shunted off to constricted environments, people with disabilities who live in, learn in, and use the community also teach their peers without disabilities new lessons in personal development, growth, and enjoyment. A nondisabled individual rarely matures or becomes a wise and complete person until she or he has empathized with others who are on the fringes of community life. We must work to broaden the community's definition of diver-

sity, building alliances across diverse stakeholders, creating a common vision of truly inclusive communities. Only then will an enabling system develop that will have the capability to endure beyond a current fad.

The time has come to adopt a new vision, one founded on the premise that the community belongs to everyone, and everyone – regardless of ability level – belongs to the community. Inclusive community leisure services that cultivate positive social interactions and friendships can be powerful vehicles for promoting this ideal. When everyone is involved actively and positively, from policy-makers and administrators to parents and consumers, we all reap benefits. Only then can equity be attained and community belonging achieved. Some day – in the not-too-distant future one would hope – inclusive community recreation programs will be available to *all* citizens. "Heterogeneous and socially inclusive" services will replace "separate but equal" services as we resolve to work toward the termination of philosophies and programs that isolate people who have disabilities from other people who do not have disabilities. We have already made substantial strides in this direction. With sustained vision, courage, and collaboration, we will successfully achieve widespread inclusive recreation services in the twenty-first century.

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Powerful Partnerships

■ Parents & Professionals

Building Inclusive Recreation Programs Together ■

Inclusive recreation services are an essential ingredient in enhancing the quality of life of children and youth with disabilities and their families. Yet fifteen years after the passage of federal and state laws providing the right to education and recreation in the least restrictive environment for all children, parents frequently find they must "fight the system" to secure inclusive services – *especially* for children with disabilities.

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